

**FASD INFORMED PRACTICE IN MENTAL HEALTH CARE**

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## Abstract

Fetal Alcohol Spectrum Disorder (FASD) is the leading cause of intellectual disability in Canada, affecting thousands of Canadians each year. It occurs due to prenatal alcohol exposure and results in a variety of cognitive, regulatory, and physical challenges. Additionally, individuals with FASD frequently experience struggles with emotional regulation and mental health disorders. Given the high prevalence of FASD in Canada, and the frequent co-occurrence of mental illness, it is highly likely that all mental health service providers will work with individuals living with FASD. However, mental health professionals are often not equipped to manage the complex needs of these individuals. This project aims to support professionals in understanding the impacts of FASD and how to adapt service delivery. A manual was created which provides information on the occurrence of FASD, the various challenges which may be present, and strategies and resources to adapt service delivery. It is the authors intention that the manual may support professionals in adopting an FASD-Informed lens in order to facilitate positive mental health outcomes for those living with FASD.

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## **Chapter One: Introduction and Overview**

Fetal Alcohol Spectrum Disorder (FASD) is the leading non-genetic cause of mental retardation in Canada and has been estimated to affect 1% of the population (The Public Health Agency of Canada, 2004), with recent research indicating that as many as 2-3% of Canadians are living with FASD (Centre for Addictions and Mental Health, 2018). FASD, which is used here as an umbrella term to capture the range of impacts, is caused through maternal alcohol consumption during pregnancy and results in a broad range of functional challenges (Popova, Lange, Burd, & Rehm, 2016a). The effects vary significantly, resulting in most individuals with FASD having unique strengths and challenges (Rutman, 2016). Factors which influence how a fetus is impacted by alcohol exposure include the stage of prenatal development during exposure, frequency and quantity of exposure, overall health of the mother, and environmental factors (Rutman, 2016). The range of deficits frequently include cognitive, regulatory, and adaptive functioning challenges (Popova et al., 2016a). While many strategies and supports can be put in place, FASD is an irreversible neurodevelopmental disability and the impacts are lifelong (Rutman, 2016).

In addition to these functional limitations, individuals with FASD are frequently impacted by mental health and related disorders. It is reported that 90% of individuals with FASD have mental health problems and as many as 95% in some studies have an additional diagnosis of ADHD (Pei, Denys, Hughes, & Rasmussen, 2011). Despite the high prevalence of mental health problems in this population, typical mental health services are not structured in a way that works for this group and their learning needs. A



lack of adaptation in many treatment programs increases the risk of treatment failure, relapse, and readmission to services (Popova et al., 2016a).

### **Project Intent**

In order to increase efficacy of mental health programs for individuals with FASD, practitioners must have a foundational understanding of this disorder and adopt an FASD-informed approach to practice. Therefore, the intent of this project is to support those working in the mental health field to better understand the disorder, identify potential challenges for clients, and to adapt service delivery. To do so, I intend to create a manual which includes introductory information about the disorder, education around common challenges, and potential strategies. My hope is that such a resource may increase FASD informed practice and provide a functional tool for all levels of mental health service delivery.

### **Rationale**

FASD presents across all demographic groups and affects all populations, creating a high likelihood that all mental health practitioners will work with individuals impacted by this disorder (Rutman, 2016). Yet, the Public Health Agency of Canada (2004) has found that many health care providers require more education on FASD. Additionally, research demonstrates that people with FASD do not generally experience success in typical programs (Rutman, 2016). By providing a resource which helps practitioners to take on an individualized approach, identifying barriers, and adapting through an FASD-informed lens, it is my hope that individuals with FASD can experience more success in mental health programs.

## **Statement of Interest**

My interest in mental health access for those impacted by FASD comes from my work in an FASD intervention program serving youth and families in Calgary, Alberta. FASD is a complicated, and frequently misunderstood diagnosis. As a result, many individuals with FASD experience poor outcomes due to under-equipped systems and a lack of adaptation in service delivery. This has significant implications for individuals, families, communities, and society as a whole. Through my experience, I've seen youth slip through the cracks of systems that are not built to support them, leading to cycles of homelessness, addiction, and criminal justice involvement. At other times, I was privileged to work with programs and professionals who strived to understand an individual's diagnoses and functional support needs. It is within these instances that I watched youth get the support that they needed and have an opportunity to demonstrate their potential. From my time in this program, all of the successes, the challenges, and the losses, inspired me to contribute to the mental health field in a way that could make a difference in the lives of those who so desperately need individualized support.

## **Overview and Structure**

This project consists of two separate parts. This first section provides an introduction to FASD and a review of the literature relevant to mental health and individualized supports. In this chapter, an overview of the project and its rationale has been provided. Chapters two and three include a literature outlining information about diagnostics, functioning, and professional implications. Methodology will be provided in chapter four followed by an overview of the limitations, reflection, and synopsis in chapter five. The second half of this project will be the manual which can act as a

separate and independent resource. The manual provides an introductory overview of FASD and the occurrence of mental health challenges. Common limitations of individuals living with FASD are reviewed, along with potential strategies and accommodations that can be used to increase accessibility and opportunities for success. Additional considerations for mental health practice are then provided, followed by suggested resources.

### **Definitions and Terms**

*Adaptation and strategies* refer to the flexibility and alteration of program structure, approach, and environment, to accommodate individuals who may function differently than the standard program population. This reflects an *individualized approach* and an understanding that it is the program and environment which must adapt, not the individual with the disability.

For the purpose of this manual, *FASD* is used as a broad term referring to the range of physical and neurological impacts of prenatal alcohol exposure in individuals with and without a formal diagnosis. Although FASD is now considered a diagnostic term, it is used here as a more general term for the purpose of discussing the broad range of individuals impacted who have another diagnosis under the FASD umbrella, or who are undiagnosed.

*FASD-informed practice* has been defined by Rutman (2016) as having awareness of the diverse brain-based impacts of prenatal alcohol exposure, making person-centered accommodations, and focussing on relationships, safety, and strengths.

*Mental health services, programs, and treatment* refer to the broad range of mental health care related services. This may involve counsellors, psychologists, social

workers, addictions workers, multidisciplinary community clinics that involve mental health components, residential treatment programs, hospital treatment programs, and community outreach. *Mental health service providers or practitioners*, as referred to in this document, pertain to all professionals working in a mental health related role.

*Prenatal alcohol exposure* is referred to in this document as any alcohol consumed during a pregnancy. Currently, there is no known safe amount of alcohol that can be consumed during pregnancy (Cook et al., 2015a). Research suggests that even low amounts of alcohol can negatively impact a fetus into adulthood (Cook et al., 2015a).

*Sentinel facial features* refer to three facial features which can be present in those with FASD. The three features: (a) short palpebral fissures, (b) indistinct philtrum, and (c) thin upper lip, have such high specificity to alcohol exposure that a diagnosis can be provided without confirmed alcohol exposure when all three features are present (Cook et al., 2015a).

*Assessment* as referred to here involves the assessment process which evaluates various domains of functioning in consideration of a possible FASD related diagnosis. *An assessment report* is referred to throughout this document and is a summary of findings and recommendations based on the assessment. This is referenced throughout this document as a tool to understand an individual's functioning and support needs.

*Diagnosis* refers to an FASD diagnosis as discussed in Chapter Two.

A range of disabilities have been observed in those impacted by prenatal alcohol exposure (Chudley et al., 2005), resulting in a variety of diagnostic terms which fall under the FASD umbrella. Additionally, the diagnostic guidelines for FASD have changed over the years, resulting in various diagnosis being given, depending on which

diagnostic tool was used. A list of the diagnostic tools and potential diagnoses are provided in Table 1. In mental health programs, clients may present with any of these diagnoses, depending on when and where they were assessed. The term *Fetal Alcohol Effects (FAE)* is not included in the table as it is no longer in use. *FAE* was originally used to capture those impacted by prenatal alcohol exposure who did not present with characteristic facial features. The term is no longer in use since the Institute of Medicine (IOM) published diagnostic guidelines in 1996 (Chudley et al., 2005). A more detailed history of diagnostics is provided in Chapter Two.

Table 1: *Diagnostic Tools and Definitions*

Diagnostic Tool	Diagnosis	Diagnosis Description
<i>The US Institute of Medicine (IOM)</i>	<b>FAS (Fetal Alcohol Syndrome) – confirmed alcohol exposure</b>	<ul style="list-style-type: none"> <li>• Evidence of facial features associated with FAS</li> <li>• Evidence of growth impairment</li> <li>• Evidence of central nervous system neurodevelopmental abnormalities seen through physical indicators or neurological impairment</li> <li>• Evidence of prenatal alcohol exposure</li> </ul>
<i>Diagnostic criteria for the IOM was collected from Chudley et al., (2005)</i>	<b>FAS – without confirmed alcohol exposure</b>	Criteria are the same as above with the exception of confirmed alcohol exposure
	<b>Partial FAS with confirmed alcohol exposure</b>	<ul style="list-style-type: none"> <li>• Confirmed alcohol exposure</li> <li>• Evidence of some facial features associated with FAS</li> <li>• Evidence of either               <ul style="list-style-type: none"> <li>➤ Growth impairment</li> <li>➤ CNS neurodevelopmental abnormalities</li> </ul> <p style="text-align: center;"><b>or</b></p> <li>➤ Evidence of abnormal behavioral or cognitive patterns that are inconsistent with development and are not explained by other factors</li> </li></ul>

	<b>Alcohol Related Birth Defects (ARBD)</b>	<ul style="list-style-type: none"> <li>• Confirmed history of alcohol exposure</li> <li>• Presence of effects which research has identified as an observed outcome of alcohol exposure</li> </ul>
	<b>Alcohol Related Neurodevelopmental Disorder (ARND)</b>	<p>This diagnosis is given when either or both of the following are present:</p> <ul style="list-style-type: none"> <li>➤ Evidence of CNS neurodevelopmental abnormalities</li> <li>➤ Evidence of abnormal behavioral or cognitive patterns that are inconsistent with development and are not explained by other factors</li> </ul>
<p><i>The 4-Digit Diagnostic Code</i></p> <p><i>Diagnostic criteria for the 4-Digit Code was collected from Astley (2004)</i></p>	<b>Fetal alcohol syndrome (alcohol exposed)</b>	<ul style="list-style-type: none"> <li>• Mild to severe growth impairment is present</li> <li>• All three facial features are present and ranked severe</li> <li>• Mild to Significant CNS Damage</li> <li>• Prenatal alcohol exposure is confirmed</li> </ul>
	<b>Fetal alcohol syndrome (alcohol exposure unknown)</b>	<ul style="list-style-type: none"> <li>• Mild to severe growth impairment is present</li> <li>• All three facial features are present and ranked severe</li> <li>• Mild to Significant CNS Damage</li> <li>• Prenatal alcohol exposure is unknown</li> </ul>
	<b>Partial fetal alcohol syndrome (alcohol exposed)</b>	<ul style="list-style-type: none"> <li>• Growth impairments present, moderate facial features, mild to severe CNS damage, and confirmed alcohol exposure</li> </ul> <p style="text-align: center;"><i>or</i></p> <ul style="list-style-type: none"> <li>• No growth impairment, moderate to severe facial features present, mild to severe CNS damage, and confirmed alcohol exposure.</li> </ul>
	<b>Static encephalopathy (alcohol exposed)</b>	<ul style="list-style-type: none"> <li>• Mild growth impairments present or none at all</li> <li>• Mild presence of facial features or none at all</li> <li>• Mild to significant presence of CNS damage</li> <li>• Confirmed prenatal alcohol exposure</li> </ul>
	<b>Static encephalopathy (exposure unknown)</b>	<ul style="list-style-type: none"> <li>• Mild growth impairments present or none at all</li> <li>• Mild presence of facial features or none at all</li> <li>• Mild to significant presence of CNS damage</li> </ul>

	<b>Neurobehavioral disorder</b>	<ul style="list-style-type: none"> <li>• Mild growth impairments present or none at all</li> <li>• Mild presence of facial features or none at all</li> <li>• CNS function is considered within the normal range</li> </ul> <p><i>This diagnosis may be given when a child is too young to formally assesses and the child should be re-assessed when they are older. This diagnosis may also be given when there was not enough evidence for CNS damage, but clinical judgement indicates CNS damage can not be ruled out.</i></p>
	<p>Additional Diagnostic categories which may be attached to a diagnosis listed above include:</p> <ul style="list-style-type: none"> <li>• <b>Alcohol exposed</b> (prenatal exposure has been confirmed)</li> <li>• <b>Alcohol exposure unknown</b> (alcohol exposure is not confirmed)</li> <li>• <b>Sentinel physical findings</b> (moderate to severe growth impairments or moderate to severe facial features are present)</li> </ul>	
<p><i>2015 Canadian Guidelines for Diagnosis</i></p>	<b>FASD with Sentinel Facial Features</b>	<ul style="list-style-type: none"> <li>• All three sentinel facial features are present</li> <li>• Alcohol exposure is either confirmed or unknown</li> <li>• Evidence of impairment in at least 3 neurodevelopmental domains</li> </ul>
<p><i>Diagnostic Criteria was collected from Cook et al., (2015b)</i></p>	<b>FASD without Sentinel Facial Features</b>	<ul style="list-style-type: none"> <li>• Evidence of impairment in at least 3 neurodevelopmental domains</li> <li>• Confirmation of prenatal alcohol exposure</li> </ul>
<p><i>Under these guidelines an additional designation has been added: <b>At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure.</b> This is not a diagnosis, but a designation given to indicate confirmed alcohol exposure potential for neurodevelopmental disfunction. This designation may be given to young children who may need to be re-assessed when older to evaluate neurodevelopmental functioning.</i></p>		

## **Chapter Two: Literature Review of FASD and Mental Health**

FASD is a complex and often misunderstood disability. The stigma associated with this disability, the various diagnostic terms, and the vast spectrum of effects, lead to societal misconceptions and a lack of awareness. This chapter aims to provide clarity through a review of the literature relevant to the occurrence, diagnosis, and management of FASD related disorders. Additionally, the review will cover the co-occurrence of mental illness with FASD, as well as treatment and ethical implications for professionals. This review is not intended to be exhaustive, but to provide a clear overview of the available information from prominent scholars who specialize in this area.

### **History of Fetal Alcohol Disorders**

Awareness of the impacts of alcohol on a developing fetus is recorded as far back as ancient times, with warnings of consumption during pregnancy found in ancient literature and biblical scriptures (Basford, Thorpe, William, & Cardwell, 2004). In the early modern period, formal warnings began to appear from the College of Physicians in England and moralistic English and American scholars. Such warnings suggested that alcoholic mothers produced children with low intelligence, strange appearances, weakness, and ill temperedness. Observations and reports continued to develop through the 1800's, and animal studies to explain this phenomenon began in the 20<sup>th</sup> century. The first formal description of Fetal Alcohol Syndrome and the deficits associated came from Jones and Smith in 1973 (Basford et al., 2004).

Since that time, understanding of the impacts of prenatal exposure has grown significantly and diagnostic frameworks have been developed. Additionally, it has been



widely acknowledged that FASD impacts all societal groups and is not isolated to women who struggle with alcoholism.

### **Progression of Diagnostics**

The diagnostic process of FASD is complex and challenging, due to the wide range of outcomes which manifest differently across the lifespan (Astley, 2004), and the challenges of obtaining accurate details of maternal alcohol consumption (Benz, Rasmussen, & Andrew, 2009). Adding to diagnostic complexity is the need for a multidisciplinary team to assess different facets of functioning (Astley, 2004). Due to these challenges, and the increasing understanding of the impacts of alcohol on the developing fetus, the diagnostic process has changed and evolved over the years.

In 1996 the United States Institute of Medicine (IOM) established a panel of experts and published recommendations for the diagnosis of Fetal Alcohol Syndrome (FAS) and related disorders (Chudley et al., 2005). Soon after, in 1997, the 4-Digit Diagnostic Code was developed at the University of Washington to establish a standardized diagnostic approach (Astley, 2004). The 4-Digit Code provided a system of measurement for four primary features of FASD: growth deficiency, sentinel facial features, central nervous system dysfunction, and prenatal alcohol exposure (Astley, 2004). In 2005, Canadian guidelines for diagnosis were published and incorporated the 4-Digit Code for diagnosis, while using the IOM to provide descriptions of the disorders (Chudley et al., 2005). Most recently, in 2015, new Canadian guidelines were published (Cook et al., 2015b) which moved away from the 4-Digit Code. The guidelines included a new diagnosis of Fetal Alcohol Spectrum Disorder (FASD) and established a new “at

risk” category for individuals who do not yet meet the criteria but present as “at risk” for the disability (Cook et al., 2015b).

Despite the many attempts to standardize and adapt diagnosis to adequately capture the population impacted by prenatal alcohol exposure, many barriers to diagnosis still exist. Due to limited funding and clinic capacities, as well as the need for multiple experts to be involved in a diagnosis, only a fraction of those impacted by alcohol exposure are diagnosed (Chudley et al., 2005). Further, there remains many educational gaps in our health care system that result in those impacted by FASD going undiagnosed or misdiagnosed. Studies have found that many physicians feel under informed on the topic, feel unprepared to discuss alcohol consumption with pregnant women, and feel uncomfortable suggesting the possibility of an FASD diagnosis due to stigma of the mother (Benz et al., 2009). A large study completed at an FASD diagnostic clinic found that 86.5% of youth had either been misdiagnosed or had received no diagnosis prior to attending the clinic (Chasnoff, Wells, & King, 2015).

### **Neuroplasticity, Treatment, and Early Intervention**

Neuroplasticity is the brains’ capacity to be shaped by experience and is essential to processes such as learning and memory (Medina, 2011). Research suggests that when the brain is damaged from prenatal alcohol exposure, a reduction in the brains’ plasticity, production of new cells, and neurogenesis occurs (Kolb, 2011). This means that the FASD impacted brain is not spontaneously changing to learn and adapt in the way a typical brain does (Kolb, 2011). While there is a great deal of research occurring to look at how plasticity can be increased in the human brain, there appears to be no related studies specifically on the brain impaired by FASD (Kolb, 2011). To address the ways to

increase plasticity in the FASD-impacted brain, more research is needed to understand the molecular mechanisms specific to this type of brain damage (Medina, 2011).

In addition to limited plasticity, FASD is a permanent disability, resulting in life long impairments (Green, Cook, & Salmon, 2015). While no treatment is known to cure FASD, intervention strategies have been shown to reduce adverse outcomes and challenges experienced by those with FASD (Green et al., 2015). There is research to support the benefits of programs that focus on self-regulation, sleep problems, speech and language development, motor function, and social skills (Carmichael Olson & Montague, 2011). Additionally, parenting programs have shown to result in positive outcomes, and the need for parenting support is considered essential. Parenting programs which focus on creating supportive environments that facilitate a child's functioning, rather than focus on behaviours and consequences, are recommended (Carmichael Olson & Montague, 2011).

Pharmaceutical interventions have been queried in treating areas of dysfunction in FASD but research specific to this is quite limited (Murawski, Moore, Thomas, & Riley, 2015). Some research has been done on the use of stimulants typically prescribed to treat ADHD, but results have been mixed, with some studies showing no improvement to attention and some identifying increased negative outcomes. Further, interventions such as nutrition and exercise have been discussed, although no clinical research has been established to measure their success (Murawski et al., 2015).

Despite limited treatment-related research, studies have found that early intervention demonstrates the highest efficacy in reducing adverse outcomes (Streissguth et al., 2004). Early diagnosis increases accessibility of appropriate school supports, allows access to valuable community programs and services, and allows for more

preparation for transitional periods, such as preparing for adulthood (Benz et al., 2009). Streissguth et al.'s (2004) research on adverse outcomes indicated that the risk of adversities was significantly reduced when children with FASD received early diagnosis and were raised in stable, nurturing homes (Streissguth et al., 2004). Regardless of the established benefits of early diagnosis and intervention, it is important to note that a diagnosis at any stage of life has great benefit. Even as an adult, a diagnosis can help identify strengths, establish realistic expectations, and increase access to supports for issues such as housing, employment, finance management, mental health, and daily living (Green et al., 2015).

### **Risk Factors**

In the mental health field, it is well established that life experiences and outcomes are greatly influenced by what are known as risk and protective factors. These factors can be biological, personal, or environmental in nature and influence life outcomes as well as how an individual will stand up to stress and negative influences. Risk factors can include family history, genetics, medical conditions, family structure, socioeconomic status, experiences of abuse or neglect, poverty, exposure to violence, and limited access to resources and services (Carmichael Olson & Montague, 2011). Individuals living with FASD appear to experience far greater adversities than the general population. For mental health practitioners working to create greater protective over risk factors to promote positive outcomes, this has significant implications. If a population experiences much higher risk factors, then far more emphasis on increasing protective factors with this population must occur in treatment.

For those living with FASD, increased risk factors include other prenatal exposures, as well as higher environmental stressors than those without FASD. Prenatal exposure to alcohol is also strongly associated with prenatal exposure to cigarettes and illicit drug which can lead to combined fetal risk factors (Carmichael Olson & Montague, 2011). After the child is born, they are more likely to experience issues such as parental substance abuse, caregiver depression, and child maltreatment (Carmichael Olson & Montague, 2011). In Streissguth et al.'s (2004) research they found that children living with FASD were also more likely to experience early parental death, abuse, and neglect; being removed from home and placed into the foster care system; experiencing repetitive periods in foster care and other transient living situations; and were more likely to be raised by foster or adoptive parents. As many of these early adversities are associated with the caregiver, it can be assumed that there are significant attachment implications to be considered as well. These combined prenatal and postnatal risks are what some scholars call 'double jeopardy' for those living with FASD (Carmichael Olson & Montague, 2011).

Early risk factors seen in those living with FASD, or higher rates of adverse childhood experiences (ACE's), coincide with disproportionately high rates of adverse outcomes later in life. Streissguth et al. (2004) found that adolescents and adults living with FASD had exceptionally high rates of disrupted school experiences; trouble with the law; confinement in a correctional, psychiatric, or addiction-based setting; repeated inappropriate sexualized behaviors; and alcohol or drug problems. Another recent study found that adolescents living with FASD experience more unstable living situations and have higher instances of living on the street or in a shelter (Flannigan et al., 2017). The

study also found more youth with FASD had criminal records or were on probation compared to youth without FASD (Flannigan et al., 2017).

### **Protective Factors**

Protective factors are influences which help to buffer an individual against stress and propels them towards positive outcomes. Protective factors can be personal traits such as intelligence, optimism, or social ability, as well as environmental factors such as community involvement, parental support, and acceptance from others. There is limited research available that directly analyzes protective factors specific to individuals living with FASD. Considering the commonality of negative outcomes, it is important to consider what protective factors can be strengthened to increase positive outcomes and buffer against the many stressors which an individual living with FASD may face. Carmichael and Montague (2011) suggest that treatment should be designed to decrease risk and promote protective factors that are considered beneficial to the general population.

In their research, Streissguth et al. (2004) were able to identify three protective factors which specifically influenced outcomes for a cohort living with FASD and which may have implications for treatment planning. The three factors were having spent much of one's life living in a stable and nurturing home, obtaining an early diagnosis, and receiving a Fetal Alcohol Syndrome diagnosis specifically. Streissguth et al. (2004) also suggested that success in school and having family advocate for academic needs may also be a strong protective factor. They conclude that collaboration between families, communities, and physicians and providing families with the necessary supports as early

as possible, will reduce negative outcomes for individuals living with FASD (Streissguth et al., 2004).

In a qualitative thesis, Radford-Paz (2013) examined risk and protective factors associated with criminality among adults living with FASD. She found four protective factors: (a) structure and supervision; (b) educational and occupational success; (c) access to clinical and financial support; and (d) having a strong network of positive influences. She indicated a need for family centered interventions to improve outcomes (Radford-Paz, 2013).

The findings from these studies have clear implications for mental health treatment if practitioners are to focus on increasing protective factors. The role of family and natural supports clearly plays an important role in reducing risk and implies that treatment should involve strengthening supports and including them as part of safety and goal planning when appropriate. Supporting clients in experiencing success also appears to be critical, and this may involve supporting them to experience felt success in treatment, advocating with other systems to support success in school and work environments, and encouraging positive activities in areas of interest which may bolster esteem and positive identity development.

### **Primary and Secondary Disabilities**

As discussed earlier, there are adverse outcomes which are frequently identified in those living with FASD. When considering these outcomes, it is important to clarify the distinction between primary disability, relating to the impacts directly resulting from alcohol exposure, and secondary disability, relating to the adverse outcomes that frequently occur because of one's deficits (Streissguth et al., 2004). Examples of primary

and secondary disabilities which frequently occur in this population are provided in Table 2.

Table 2: *Primary vs Secondary Disabilities*

<b>Primary Disabilities</b> Directly Resulting from CNS dysfunction caused by prenatal exposure.	<b>Secondary Disabilities</b> Challenges that develop during one's life and can be prevented - often influenced by the struggles related to primary disabilities
Poor Memory	Negative Peer Relationships
Impulsivity	Depression
Problem Solving Challenges	Social Isolation
Learning Deficits	Homelessness
Emotional Dysregulation	Violence and Aggression
Slow Thought Process	School Failure
Difficulty Expressing One's Self	Defense Mechanisms such as resistance, anger, or avoidance of important tasks

Note. Adapted from "Primary and Secondary Disabilities of FASD," by The FASD Justice Committee, 2018.

Streissguth et al.'s (2004) research on secondary disabilities in over 400 individuals impacted by FASD found that 60% of adolescents and adults experienced disrupted schooling, 60% had trouble with the law, 48-52% had demonstrated inappropriate sexual behavior, and 50% had been confined for hospital treatment or in the justice system. These secondary challenges, which interact with primary deficits, have significant implications in day-to-day life, survival, and capacity to thrive (Rutman, 2011). Not only do these secondary challenges impact the well being of the individual with FASD, they can also bring lifelong consequences to the individual's family and supports (Carmichael Olson & Montague, 2011).

### **Mental Health Occurrence and Impact**

While mental health challenges have often been accepted as secondary disabilities in those with FASD, recent evidence suggests that mental illness and related disorders are



primary disabilities, which may be directly linked to alcohol exposure and fetal development (Rutman, 2011). There is now evidence that prenatal alcohol exposure causes changes to stress pathways and stress related brain function, which may influence the development of related disorders (Green & Salmon, 2016). Regardless, the occurrence of mental illness and FASD is significant. As stated earlier in this paper, 90% of individuals with FASD have been described as having mental health problems (Pei et al., 2011). Some of the most prevalent issues are depression, mood and anxiety disorders, conduct disorder, psychopathology, and ADHD which has been seen in up to 95% of some study participants (Pei et al., 2011). With ADHD being the most commonly noted co-occurring disorder, it is important to note that ADHD can present differently in an individual with FASD (Ontario Center for Excellence for Child and Youth Mental Health, 2014). Children with FASD can have earlier onset of ADHD symptoms, present with unique attention related deficits, and can react differently to medications (Ontario Center for Excellence for Child and Youth Mental Health, 2014).

**Problematic substance use.** In addition to frequent struggles with mental illness, studies have found that those impacted by FASD are also more likely than the general population to struggle with substance abuse. Multiple studies have found a strong correlation between prenatal exposure to alcohol and problematic alcohol use later in life (Pei et al., 2011). In a large study by Alati et al. (2006 as cited in Pei et al., 2011), 25% of young adults with a PAE diagnosis also had an alcohol disorder and 6.1% were alcohol dependant. One study of young adults at the University of Washington found 60% of participants with an FASD diagnosis met criteria for a substance abuse disorder (Famy, Streissguth, & Unis, 1998). Another study found that prenatal alcohol exposure

significantly influenced later dependence on alcohol, nicotine, and illicit drugs (Pei et al., 2011).

**Suicidality.** Suicidality has also been identified with high frequency. Most notably, a study by Streissguth and colleagues (1996 as cited by Huggins, Grant, O'Malley, & Streissguth, 2008) found that those with FASD attempted suicide at five times the national average. Another study found that those with FASD who had attempted suicide, had higher rates of mental health diagnosis, substance use disorders, history of trauma and child abuse, and a lack of social supports (Huggins et al., 2008). It is possible that the high incidence of adverse life experiences in this population contributes to high rates of suicidality. Bell (2018) also suggests that trouble with affect regulation likely contributes to high rates of suicide in the FASD population, whose current life expectancy averages only 34 years.

**Treatment.** Despite high instances of mental illness, many individuals with FASD are excluded from, or do not experience success in mental health treatment programs. Challenges with behavior, learning, and cognitive disabilities, make it difficult for those with FASD to qualify for treatment programs and to experience success when admitted (Nicholson, 2008). Additionally, few treatment programs exist in Canada for adults with co-occurring FASD and mental health or substance use problems (Nicholson, 2008).

With low success rates and frequent re-admission, comes a significant economic and societal cost. FASD imparts a large burden on society through the health care system, mental health and substance abuse treatment services, as well as systems such as foster care and criminal justice (Popova et al., 2016a). Health care costs for a child with FASD

are estimated at nine times the national average in the U.S. (U.S. Department of Health and Human Services, 2014). In Canada, the estimated health care cost associated with individuals with FASD in 2009 was over 6.7 million, with the cost for psychiatric care alone at 1.2 million, and substance use treatment between 2 and 5 million (Popova et al., 2016a). These estimates are based on conservative calculations and it is suspected that the actual health care cost for individuals with FASD may be as high as 48 million annually (Popova et al., 2016a). Further to the economic costs are the burdens faced by individuals not experiencing treatment success, and the grief and loss experienced by their loved ones.

### **Ethical Implications**

From a social justice perspective, it is imperative that all individuals have equal access and opportunity to engage in mental health treatment. Those impacted by FASD have a fundamental right to accommodations that support them in accessing and succeeding in treatment programs. Rutman (2016) argues that programs need to be designed and delivered in ways that are FASD-informed, promoting health and wellness in ways that consider the needs and challenges of those living with FASD. The call to provide accommodations and to be sensitive to diversity is a strong imperative in most professional code of ethics. The Canadian Counselling and Psychotherapy Association's ethical principles (CCPA, 2007) call on practitioners to be proactive in promoting the best interest of clients (a), to respect the dignity and just treatment of all persons (e), to refrain from causing harm (c), and to be responsible to society. In promoting the best interest of clients, the Code of Ethics (CCPA, 2007) requires practitioners to strive to understand the diversity of their clients, including differences related to disability (A10).

The Canadian Code of Ethics for Psychologists (Canadian Psychological Association, 2017) requires practitioners to practice in such a way that they contribute to the fair distribution of benefits to individuals and groups (I.11). It also requires practitioners to practice responsible caring, including the promotion of well-being, avoidance of harm, and striving to provide accessible service (II.1; II.2; II.18). Additionally, the code includes responsibility to society, requiring practitioners to change aspects of the discipline that detract from just and beneficial societal change (IV.19).

### **Chapter Summary**

This chapter covered basic information about the diagnosis, management and implications of FASD. Key points from this chapter include:

- ✓ There is no cure for FASD. The primary disabilities which occurred directly from alcohol exposure in the womb will exist throughout the life span. Research shows that through early intervention, appropriate supports and accommodations, secondary disabilities such as mental illness and antisocial behavior can be prevented.
- ✓ Diagnosis of FASD is complex. As such, many individuals do go undiagnosed. Service providers must be aware that they do provide services to individuals with FASD whether the client presents with a diagnosis or not.
- ✓ There is a high occurrence of mental illness in those impacted by FASD. However, this population often experiences poor outcomes in mental health treatment. This is likely due to ill equipped services, a lack of knowledge, and cognitive based programming.

- ✓ Accommodations are an ethical imperative. It is the responsibility of mental health service providers to adapt services in a way that facilitates success for individuals living with FASD. Providers must identify functional barriers and engage in reflexive practice.

### **Chapter Three: Literature Review of Practice Implications and Potential Client Challenges**

In the previous chapter, foundational knowledge of FASD and the implications for mental health practitioners were explored. Chapter three focusses on the mobilization of knowledge. A brief synopsis of counselling recommendations and practice models is provided, pointing to the need to develop individualized, informed, and flexible practice approaches. As such, common challenges which impact those living with FASD are then explored in addition to strategies and recommendations found in the literature. As the effects of prenatal alcohol exposure vary considerably, it is important to recall that challenges discussed in this chapter have been found common in this population but may not apply to all individuals impacted by FASD. Similarly, everyone may be impacted differently, and to varying degrees within each category.

#### **FASD Counselling Recommendations**

Pei, Flannigan, Walls, and Rasmussen (2016) have highlighted the fact that despite well documented needs and costs of those with FASD, there is limited research of effective interventions with this population. This is attributed to the diverse needs of these individuals and the challenges of collecting meaningful information across multiple contexts and capacity levels (Pei et al., 2016). This challenge carries over to designing

and publishing suggested accommodations as there is no blanket approach that can be taken or a single set of strategies that are likely to be effective (Tremblay et al., 2017). The limited ability to design standard interventions is unique to FASD due to the effects varying considerably (Rutman, 2016).

Despite these limitations, some generalized counselling recommendations do exist in the literature. The U.S. Department of Health and Human Services (2014) suggests that counsellors should first assess safety risks and implement safety plans as needed. This includes assessing for any risk related to victimization, secure housing, access to food, abuse, suicide, or risk of judicial involvement. Once safety is established, they suggest the following adaptations to treatment planning: (a) provide a structured program and environment; (b) share simple rules early and often, avoiding punitive measures when clients are not able to follow expectations; (c) take a holistic approach, focussing on all areas of living, and considering the likelihood of co-occurring issues; (d) include the individual and the support system in future planning; (e) incorporate a variety of learning methods; (f) consider sensory needs; and (g) arrange for aftercare to support the client after discharge. The Department also suggests potential focal points of counselling to include setting boundaries, coping with loss, and self-esteem (U.S. Department of Health and Human Services, 2014).

Brown (2017) suggests that mental health practitioners keep things simple, focussing on one or two tasks at a time, and that they avoid overestimating client comprehension based on a client's verbal expression or talkative nature. Further, he suggests therapeutic approaches which focus on modeling, coaching, teaching, and skill building, as opposed to cognitive or insight-based treatments which may not be effective

(Brown, 2017). Similarly, some scholars recommend the use of expressive therapies when working with individuals with FASD. Akram and Khan (2017) explain that expressive therapies act as an alternative to talk therapy, utilizing creative means such as dance, music, and play to help clients explore difficult issues and emotions. They report that such methods can be extremely valuable for all individuals living with intellectual disabilities, who may experience limitations in traditional talk therapy formats (Akram & Khan, 2017). Animal assisted therapy has also been recommended, based on the physical, emotional, and social benefits it has shown in others with similar disabilities (Vincent, Kropp, & Byrne, 2014). Finally, art therapy has also proved to be a useful technique for addressing issues of trauma in individuals living with FASD (Bugher & Brown, 2016; Gerteisen, 2008).

**Teaching self-advocacy.** As part of a holistic approach to care, mental health practitioners should focus on equipping individuals living with FASD to be self-advocates, promoting the skills needed to seek help and identify their needs to others. While literature pertaining to the development of self-advocacy skills for those with FASD is limited, the general disability literature emphasizes the critical nature of these skills. For example, a literature review focussed on self-advocacy for individuals with disabilities found the following consensus among scholars: (a) a first step towards self-advocacy is to equip individuals with knowledge of themselves, understanding their strengths, weaknesses, learning styles, and preferences; (b) secondly, individuals need to understand what their rights are as people living with a disability; and (c) individuals must gain communication skills to be able to communicate their needs, and to say no when appropriate (Test, Fowler, Wood, Brewer, & Eddy, 2005).

The Alberta Learning's Special Programs Branch (2004) suggests that students with FASD can learn how to self-advocate through strategies such as role play or social scripting. They also suggest involving students in setting goals for themselves and developing learning plans, to help strengthen self-advocacy and self-determination skills. Additionally, the branch recommends a Self-Advocacy Checklist be used to assess the student's current ability to self-advocate. Their proposed checklist includes questions such as "I know what FASD is," "I ask for help when I need it," and "I set goals for myself" (The Alberta Learning Special Programs Branch, 2004).

Similar strategies could be implemented in mental health settings, using social scripting and role play to practice self-advocacy. Mental health professionals could also formally or informally assess current advocacy capacity by exploring the client's current understanding of their challenges and needs, and how they communicate these to others. Capacity building in this area may also consider roles of authority and practicing how to identify needs with authority figures such as police, care providers, or physicians.

**Professional development.** There is expert consensus that professionals supporting individuals with FASD should have access to ongoing professional development and consultation specific to this disability. Brown et al. (2018) states that mental health professionals must receive advanced training on FASD to increase the likelihood of individuals with FASD receiving appropriate and effective services. In addition to training on the effects of prenatal alcohol exposure, they recommend professionals familiarize themselves with each client's unique strengths and coping styles (Brown et al., 2018). Rutman (2016) advocates that professional development related to FASD must be an ongoing effort in order to continually be deepening ones understanding



of FASD. She suggests that professionals' access face-to-face and web-based trainings, in addition to engaging in reflective practice discussions with colleagues, supervisors, or community partners (Rutman, 2016). Similarly, Tremblay et al. (2007) recommend clinicians engage in consultation and supervision specific to FASD to enhance their efficacy with these clients. Tremblay et al.'s (2007) study found that regular communication and reflective meetings with FASD experts allowed practitioners to learn new ways to problem solve, and to feel a greater sense of competency.

### **FASD Practice Frameworks**

In addition to the strategies discussed above, some prominent scholars have offered broad frameworks for practice with individuals living with FASD:

- Pei et al., (2015) propose four principles of best practice to meet the needs of this diverse population based on the literature. They suggest (a) consistency, including long term relationships and consistent support structures; (b) collaboration across systems, including time for collaborative meetings and establishment of common goals, messaging, and approach; (c) interdependence, including planning and preparation for transitions, and life-long supportive environments; and (d) proactivity, including early intervention. They suggest that a FASD approach requires training of professionals from a brain-based disability lens that allows them to shift expectations (Pei et al., 2015).
- Tremblay et al. (2017) suggest that a fluid and responsive approach, focussed on communication and reflection will allow for supportive adaptation. They argue that it is incumbent upon agencies and broader systems to support front

line professionals in dealing with these challenges and in adapting service delivery to best serve individuals in this population (Tremblay et al., 2017).

- Rutman, (2016) suggests that programs adopt an FASD-informed approach which “recognizes that to achieve positive outcomes, it is the system, program, and/or services providers who need to make modifications rather than the person with FASD.” She suggests programs consider client failure as a possible brain-based disability, requiring environmental accommodations. She further articulates an FASD-informed approach to be safety and relationship based, encompassing awareness, strength-based perspectives, and person-centered accommodations (Rutman, 2016).

Based on the approaches discussed above, individualized practice, education, and flexibility are critical to supporting individuals with FASD. For this reason, the remaining chapter aims to explore the literature pertaining to common challenges, so that individualized adaptations can be navigated. The literature is grouped into broad functional categories, each presenting relevant findings, interventions, and accommodation found in the literature: (a) memory, (b) communication, (c) academics, attention, and processing, (d) executive functioning, and (e) adaptive functioning.

## **Memory**

Memory deficits are frequently discussed in the literature pertaining to FASD (Kully-Martens, Pei, Job, & Rasmussen, 2012; Rasmussen, 2005) and numerous studies have found significant memory deficits in this population (Rasmussen et al., 2013). Memory deficits may include encoding, storage, and retrieval of information (Kully-Martens et al., 2012; Millar et al., 2017;), as well as verbal, visual, and working memory

domains (Kully-Martens et al., 2012). Research by Kully-Martens et al. (2012) noted significant memory impairments associated with FASD and the impact of these deficits on daily functioning. They found that individuals with FASD can struggle to recall the source of information or to differentiate old and new information (Kully-Martens et al., 2012). Essentially, individuals with FASD were remembering less information and frequently recalling inaccurate information (Kully-Martens et al., 2012). These challenges make it difficult for individuals to differentiate reliable vs. unreliable information, discern real life from fantasy, and perceive the intent of others which increases their vulnerability of being misled (Kully-Martens et al., 2012). When unidentified, these deficits can appear to be behavioral in nature, leading others to assume an individual is being lazy or defiant, when these are symptoms of a neurologically-based disability (Kully-Martens et al., 2012).

Other studies have found struggles with facial memory (Wheeler, Stevens, Sheard, & Rovet, 2012), spatial memory, and working memory (Rasmussen, 2005). For deficits in working memory, strategies have been suggested such as the use of visual aides and checklists, and providing consistency, structure, and routine (Rasmussen, 2005; Rutman, 2016). Additionally, appointment reminders (Rutman, 2016; Tremblay et al., 2017) and consistently scheduled appointments (Rutman, 2016) are suggested. Given the common memory deficits seen in this population, practitioners must remember that difficulties with punctuality and attendance may not be indicative of a lack of interest or cooperation, but again the result of a brain-based issue (Rutman, 2016). Professionals must also note that memory deficits can be inconsistent, and that clients may have

remembered something many times before but are unable to remember again on any given day (Millar et al., 2017).

### **Communication**

Children with FASD have been reported to exhibit a number of communication related challenges, including word articulation, naming, comprehension, and both receptive and expressive language (Wyper & Rasmussen, 2011). Receptive communication deficits may include problems with: following instructions, comprehension of what is being said, discrimination of verbal information, generalizing, understanding and using abstract language, and sequencing (Millar et al., 2017). Expressive language deficits may involve difficulty with complex language structures and problems retrieving words from memory (Millar et al., 2017). Wyper and Rasmussen (2011) found that children with FASD had significantly lower receptive and expressive language scores than control children. Proven, Ens, and Beaudin (2014) also found that 85% of FASD participants in their study had language impairments, with 65% showing severe impairment, and 16% demonstrating mild to moderate core language deficits.

Based on deficits with communication, it can be predicted that individuals in mental health programs may struggle with understanding expectations, instructions, and psychoeducational programming. Additionally, they may struggle to express their feelings and experiences in a meaningful way. Rutman (2016) recommends the use of clear and concrete language, brief sentences, and providing time for individuals to process information. Tremblay et al. (2017) also suggests using concrete communication, avoiding jargon, and demonstrating concepts in a way that make sense for the individual. Additionally, it should not be assumed that a client has retained information, instead

frequent check ins to gage understanding are recommended (Rutman, 2016). As an alternative to talk therapy, expressive approaches have also been suggested. In Gerteisen's (2008) experience, art therapy provides a means of nonverbal expression at a sensory level that can be easily understood. She found that the act of drawing can provide stimulus to overcome difficult feelings, address issues of trauma, and provide a means of telling one's story (Gerteisen, 2008).

### **Academics, Attention, and Processing**

In addition to the core cognitive deficits experienced by individuals with FASD, these challenges can be compounded by deficits in academics, attention, and processing speed. Academically, students with FASD frequently experience deficits in reading, spelling, and math, and often require special education services (Pei et al., 2016). In adulthood, these academic deficits may contribute to high rates of unemployment (Pei et al., 2016) and deficits with life skills related to written communication and basic math foundations. Another frequent struggle exists with attention, and attention deficits are the most common neurodevelopmental disabilities seen with FASD (Cook et al., 2015a; Kodituwakku, 2009; Pei et al., 2011). Studies have found deficits related to attention include difficulties with vigilance, sustaining attention over time, focussing, and shifting attention (Kodituwakku, 2009). Further, numerous studies demonstrate that individuals with FASD may process information more slowly, especially information that is complex or requires increased effort (Kodituwakku, 2009).

## **Executive Functioning**

Executive functioning involves a group of higher order cognitive processes such as self—control, flexible thinking, planning, judgement, organization, and understanding cause and effect (Millar et al., 2017). Deficits in this area can result in individuals who do not understand or learn from consequences (Millar et al., 2017), have trouble planning or being organized, are unaware of their own challenges and difficulties, and struggle with judgement, comprehension, and abstract concepts (Mariasine, Pei, Poth, Henneveld, & Rasmussen, 2014). Some studies have noted significant areas of deficit to be working memory and inhibition (Kingdon, Cardoso, & McGrath, 2016; Rai et al., 2017), as well as vigilance (Kingdon et al., 2016). Other studies have identified impairments in individuals with FASD in all areas of executive functioning, regardless of whether individuals present with sentinel facial features (Rasmussen, 2005). Additionally, IQ has been found to not consistently relate to executive functioning deficits (Rasmussen, 2005). This suggest that neither IQ, nor facial features, act as a reliable indicator for executive functioning deficits in this population.

As executive functioning skills are essential for navigating daily life, deficits in this area can have significant consequences. For example, Rasmussen (2005) explains that a lack of sufficient inhibitory control, and not understanding consequences, can lead to adverse experiences such as devastating justice system involvement. Despite the high risks, Rasmussen (2005) reports limited research efforts to support executive functioning interventions with this population. However, Rutman (2016) suggests providing reminders of appointments and activities, consistent scheduling, using a hands-on approach, modeling and role-playing desired behaviors, experiential learning

opportunities, and ongoing support and check in's. Watson and Westby (2003) also suggest social stories, implementing visual aids and organizational tools, providing opportunities to practice social skills, language and social skills training, training in emotion identification, and coaching through interactions.

Brown et al. (2018) urge mental health professionals to assess for executive functioning deficits in clients with FASD. They articulate that executive functioning deficits, such as struggles to understand consequences, predict outcomes, or navigate social expectations, are often misinterpreted as malicious or intentional behaviors. Such misinterpretations can lead to ineffective treatment planning or inaccurate mental health diagnosis. As such, it is critical for mental health professionals to assess and identify executive functioning deficits in order to provide the appropriate interventions (Brown et al., 2018).

### **Adaptive Functioning**

Much like executive functioning, adaptive functioning is required to meet the demands of daily life (Mariasine et al., 2014). Adaptive functioning can be conceptualized into the following three domains: (a) communication: receptive, expressive, and written; (b) daily living skills: eating, dressing, household management, management of time, money, use of a telephone, and work performance; (c) socialization: ability to interact with others, use of leisure time, and development of coping skills (Fagerlund et al., 2012). Adaptive functioning deficits are common among individuals with FASD who often struggle with employment and independent living (Mariasine et al., 2014). While these deficits are clearly present in childhood, it appears that they persist or worsen with age, resulting in significant impairments and maladaptive

behaviors in adolescence and adulthood (Crocker, Vaurio, Riley, & Mattson, 2009; Pei et al., 2016;). A study by Fagerlund et al. (2012) found that adaptive functioning abilities in children with FASD are significantly compromised, and that children with FASD demonstrate poorer adaptive functioning capacity than peers with similar IQ scores from other disability groups. This indicates again that IQ may not be a clear measure of daily functioning in this population. Another study by Jirikowic, Kartin, and Carmichael Olson (2008b) found especially poor results in adaptive functioning involving socialization, personal living, and community living skills.

Pei et al. (2016) report a significant gap in the literature pertaining to adaptive functioning interventions for individuals with FASD, noting that existing literature focusses only on basic safety and social interactions (Pei et al., 2016). While many studies call for interventions, few suggest what interventions may be appropriate. It does appear that the caregiving environment through childhood influences the development of adaptive functioning skills in this population (Crocker et al., 2009; Fagerlund et al., 2012) indicating a need to support healthy families and home environments to achieve better outcomes. Jirikowic et al. (2008b) suggest reframing developmental expectations and implementing accommodations such as visual schedules. Additionally, Mariasine et al. (2014) suggest focussing on strengths and shifting perceptions from negative behaviors to brain-based disabilities.

### **Emotional and Affect Regulation Challenges**

Numerous studies have noted a high prevalence of affect related disorders (Pei et al., 2011; Popova et al., 2016b), as well as negative emotionality or intense negative moods (Cook et al., 2015a). Rutman (2011) identified challenges with emotional



regulation as a primary effect of FASD and provided the example of individuals who quickly get overwhelmed, turning from calm to agitated in seconds. The US Department of Health and Human Services (2014) describes individuals with FASD as having a possible tendency towards explosive episodes. Research by Greenbaum, Stevens, Nash, Koren, and Rovet (2009) has identified that a core deficit of FASD may be difficulty identifying emotions or feelings, and difficulty understanding or interpreting the mental or emotional state of others. Further, animal research has found prenatal alcohol exposure to affect neurotransmitters involved in stress and mental health (Cook et al., 2015a).

Affect regulation was recently added to the new Canadian Guidelines as an assessment domain to be considered in diagnosing FASD (Cook et al., 2015b). Criteria for meeting impairment in this domain requires an individual to meet DSM criteria for Major Depressive Disorder, Persistent Depressive Disorder, Disruptive Mood Dysregulation Disorder, Separation Anxiety Disorder, Selective Mutism, Social Anxiety Disorder, Panic Disorder, Agoraphobia, or Generalized Anxiety Disorder (Cook et al., 2015a). The panel responsible for including Affect Regulation in the new diagnostic guidelines did so based on the prevalence of mental health disorders in the FASD population (Cook et al., 2015a).

### **Additional Regulatory Considerations**

From a neurological perspective, one of the regions of the brain most commonly impacted by prenatal alcohol exposure is the hypothalamus which is responsible for many basic instincts (Badry, Hickey, & the Tri Province FASD Research Team, 2014). Damage to this region may impact functions such as eating or appetite behaviors, emotions related to fight or flight, and processing sensations related to temperature and pain (Badry et al.,

2014). Literature pertaining to deficits in each of the regulatory functions of the hypothalamus appears limited. However, some studies have been done which examine sensory processing, sleep, and hunger.

**Sensory Processing Difficulties.** Sensory processing is the neurological process of retrieving, modulating, and integrating sensory information (Jirikowic et al., 2008a). Individuals with sensory processing disorders tend to unreliably interpret and organize sensory information (Jirikowic et al., 2008a). In individuals with FASD, this challenge has been connected to struggles with adaptive behavior, higher level learning (Jirikowic et al., 2008a; Pei et al., 2016), social-cognitive functioning (Jirikowic et al., 2008a), sensory-motor integration, and motor development (Pei et al., 2016). These challenges can impact one's ability to meet expectations and achieve success across multiple environments (Jirikowic et al., 2008a).

A study by Hansen and Jirikowic (2013) found that 81.8% of the children with FASD in their sample had some problems or definite dysfunction related to sensory processing in the home. In Franklin, Deitz, Jirikowic, and Astley's (2008) study, findings also indicated high levels of sensory processing challenges, showing a significant correlation between these deficits and problem behaviors. They suggest that sensory based deficits impact the ability of an individual with FASD to respond adaptively to their environment (Franklin et al., 2008). Further, they suggest that problem behaviors can be reduced through modification of the environment, and caregiver and teacher education about this issue (Franklin et al., 2008).

**Sleep.** Chen, Carmichael Olson, Picciano, Starr, and Owens (2012) state that sleep problems are commonly reported among children with fetal alcohol spectrum

disorders. In their study of children with FASD, Chen et al. (2012) found that 85% of their sample demonstrated sleep dysfunction. They note that disrupted sleep cycles are associated with health and behavioral problems such as poor school performance, neurocognitive deficits, inattention, unstable moods, as well as metabolic and cardiovascular issues (Chen et al., 2012).

Another study by Ipsiroglu, McKellin, Carey, and Looock (2013), looked at how and why sleep problems are often missed in this population. They found that diagnostic attention was typically focussed on day time functioning and that individuals with FASD were typically treated for daytime behavioral and emotional problems, missing possible underlying sleep issues. They also found feelings of desperation and lower quality of life for caregivers due to sleep deprivation. The findings from these studies indicate a need to consider sleep issues as a possibility in individuals with FASD and to consider sleep related treatment to improve day time functioning (Ipsiroglu et al., 2013).

**Hunger.** The regulation of hunger is another commonly reported issue among this population. It has been reported that infants with FASD demonstrate reduced suckling ability and delayed transition to solid food (Amos-Kroohs et al., 2016). Additionally, older children demonstrate poor eating habits such as constant eating, poor satiety, low appetite, and below recommended nutrient intake. In their research, Amos-Kroohs et al. (2016) found that 31.1% of the sample snacked constantly, and 23% were never full or satisfied. Other children were reported to have very low appetite and little interest in meal times. Further, children with FASD were more likely to have been diagnosed as underweight (Amos-Kroohs et al., 2016).

Another study found that 50% of females were overweight, while 37% of males were low weight, or had reduced stature or body mass index (Werts, Van Calcar, Wargowski, & Smith, 2014). A third study found 36.8% of the sample had problems with constant snacking, 26% had a lack of satiety, and 31.6% were picky eaters or had poor appetite. Additionally, high rates of constipation and excessively high sugar intake were noticed. The authors indicate that children with prenatal alcohol exposure may be at risk for nutritional deficiencies and disordered eating (Werts et al., 2014). These studies indicate possible challenges with regulating food consumption which should be considered when supporting individuals with FASD. Food intake is critical to daily functioning and may require monitoring or support to regulate healthy consumption.

### **Physical Implications**

FASD is a whole-body disorder which can impact all developing cells of an exposed fetus. Despite much focus on the central nervous system, it is well known that there are many physical implications. Commonly reported issues include growth impairments, deviations in facial features, poor motor control, and high instances of co-morbid medical conditions. In fact, one of the first indicators which brought attention to FASD was growth deficiencies (Cook et al., 2015a). Growth deficiencies are known to include abnormally low height and weight, as well as an inability to gain weight even into adulthood (Del Campo & Jones, 2017). In the new Canadian Guidelines for diagnosing FASD, growth has been removed from diagnostic criteria due to its reported lack of specificity to the disability (Cook et al., 2015a). However, growth and physical implications are well documented in this population and Cook et al. (2015a), who

established the new guidelines, note a high prevalence of intrauterine growth restriction, small stature, motor clumsiness, problems moderating grip, and issues with balance.

Motor functioning, which continues to be a diagnostic consideration for FASD, includes challenges in fine motor, gross motor, graphomotor, and visual-motor abilities (Cook et al., 2015a). Combinations of muscle tone, reflexes, balance, coordination, and strength are also considered (Cook et al., 2015a). Millar et al. (2017) also noted deficits with coordination and muscle tone, impacting activities such as running, bike riding, sports, writing, pencil holding, tying shoes, or using scissors.

In addition to growth and motor, many other physical challenges and comorbid disorders have been reported. In 1973, Jones and Smith (as cited in Del Campo, & Jones, 2017) first defined Fetal Alcohol Syndrome (FAS) and made note of the growth deficiencies. They also reported high instances of microcephaly, joint limitations, deficits of the heart, and most notably, sentinel facial features. A review of comorbid disorders and FASD identified significantly high rates of hearing loss, visual impairment, and blindness compared to the general population (Popova et al., 2016b). Many conditions were also noted as having high frequency of comorbidity to FASD including malformation of the spine, cleft lip and cleft palate, urinary system malformation, musculoskeletal deformities, as well as respiratory, digestive, and organ related dysfunction (Popova et al., 2016b). A study by Stade, Stevens, Ungar, Beyene, and Koren (2006) found that children and youth with FASD have significantly lower health related quality of life than those of the general Canadian population. Additionally, a recent self-report survey by Travis, Himmelreich, and Lutke, which is yet to be published, found that individuals with FASD report much higher incidences of health conditions than the

general population (Givetash, 2017). Some of the conditions more frequently reported by these individuals include rheumatoid arthritis, celiac disease, and autoimmune or cardiovascular disease (Givetash, 2017).

### **Chapter Summary**

This chapter explored research findings related to the impacts of FASD and effective strategies. The following are key points from this chapter:

- ✓ The practice frameworks have been provided by prominent scholars in the area of FASD. The frameworks emphasize the need for consistency, flexibility, reflectivity, collaboration, knowledge, and a strengths-based approach.
- ✓ Prenatal alcohol exposure impacts the whole developing body. In addition to a variety of functional issues with the central nervous system, alcohol exposure affects physical development as well, including the skeletal and muscular systems and organ development.
- ✓ Research of effective interventions is limited. There is a significant gap in the literature pertaining to interventions across functional domains. Regardless, many scholars suggest adaptations and accommodations to service delivery.
- ✓ Capacity goes beyond IQ. Studies found that IQ did not consistently reflect the functioning of individuals living with FASD who frequently suffer from adaptive and executive functioning skills which are required to function independently. This indicates that clients who present with average or high IQ, may still experience significant struggles that require consideration.

## Chapter Four: Methodology

The intent of this project was to develop a manual which could be utilized by mental health professionals to better understand the impacts of FASD and how to adapt service delivery. This chapter provides an overview of the process in which this project was completed. A description of research methods is provided, outlining databases, search terms, and resources used. Ethical guidelines and considerations used in the creation of this project are also discussed.

### Research Methods

A variety of databases were searched using the University of Lethbridge online library catalogues and Google Scholar including Academia, Sage Journals Online, ProQuest (Nursing & Allied Health Database), Summon, The National Center for Biotechnology Information (NCBI) Online, PsycNet, Wiley Online Library, Taylor & Francis Online, ScienceDirect, EBSCOhost, and SpringerLink. Some of the search terms included: *FASD, fetal alcohol, prenatal alcohol exposure, fetal alcohol spectrum disorder, FASD mental health, FASD economic costs, FASD secondary disabilities, and FASD best practice*. Articles were included based on the recency of publication, empirical support, and relevance to the topic. Additionally, a number of scholarly web-based resources were used including: *the FAS Diagnostic & Prevention Network, the AB FASD Child Welfare Caregiver Curriculum, the Canada FASD Research Network, the Centre for Addiction and Mental Health, and the Government of Alberta FASD Learning Series*.

## **Creation of the Manual**

The basic structure of the manual was designed to introduce the effects of prenatal alcohol exposure and provide strategies and considerations for making mental health treatment more accessible to those living with FASD. The findings from the literature review provide a base of information in the manual. However, many of the strategies and suggestions found in the manual are based on creative ideas and personal experience designing strategies and accommodations for individuals living with FASD.

## **Ethical Considerations**

This project did not require human participants for data collection. The information discussed throughout this document and the manual was gathered through available literature and resources located only by myself, and presented in a way that is lawful and accurate. Due to a lack of empirical evidence surrounding best practices and strategies specific to FASD, many of the strategies provided in the manual are based on personal work experience and they are not empirically based. Additionally, each individual living with FASD is impacted uniquely. As such, not all challenges and strategies discussed will be applicable to each client with FASD.

## **Chapter Five: Synopsis**

The intent of this project is to develop a manual which can be used to assist mental health professionals in adapting service delivery to meet the needs of individuals impacted with FASD. The previous chapters provided an overview of the project and the rationale. This chapter will provide an overview of the manual itself, the target



population, knowledge transfer, potential benefits of the manual in working with individuals impacted with FASD, and limitations to the manual.

### **The Manual**

The manual acts as an informational resource for mental health practitioners. It breaks down misconceptions about FASD, provides critical information for understanding the disorder, and provides strategies to help mental health practitioners shift their practice to better support individuals impacted by the disorder. The manual also provides detailed descriptions of common challenges, supported by empirical research, to help the reader fully understand the range of impacts of prenatal alcohol exposure and how these impacts may present. The structure of the manual is broken down into six parts as follows:

- ✓ An Introduction to FASD
- ✓ FASD and Mental Health
- ✓ Central Nervous System Dysfunction
- ✓ Central Nervous System Dysfunction and Regulation
- ✓ FASD as a Whole-Body Disorder
- ✓ Program Considerations to Promote Success

### **Knowledge Transfer**

This manual will provide mental health practitioners with a foundational knowledge base for understanding the impact of prenatal alcohol exposure and the life-long implications faced by many individuals living with FASD. Throughout the manual, information, tools, and resources are provided to generate reflective practice around client

challenges and individualized treatment. The information can be applied and adapted across a variety of settings.

Introductory information about FASD and the co-occurrence of mental illness is discussed in the first two sections of the manual. This knowledge may increase professional awareness of both FASD, and how mental illness uniquely impacts those living with the disability. The first two sections provide a foundation of which to build on throughout the remainder of the manual.

The following three sections review various challenges that can be present for individuals living with FASD. The breakdown of challenges intends to act as a quick reference guide for professionals. Each identified challenge provides information about how it may impact the individual in mental health settings, and how to adapt service delivery. In many instances, the strategies provided will also need to be adapted to fit for individual clients. However, they can act as a starting point to generate reflective practice and creative adaptations to promote success. The individualized nature of FASD is stressed throughout this manual, reminding readers that each client will have a variety of functional strengths and weaknesses, and may not present with each of the challenges discussed. In this way, much consideration should be given to how each client is impacted uniquely, and treatment plans can be structures accordingly. Further, the strategies provided are easily adaptable, allowing professionals to consider alternatives that may better fit with a client's cultural preferences or worldview.

The final section of the manual explores further practice considerations, such as intake and assessment considerations, increasing protective factors, and how to promote long term success. This section reflects best-practices found in the literature specific to

service delivery for individuals living with disabilities. It is intended that the information provided may be beneficial across all levels of service delivery. Front line staff may use the manual as a tool to guide their practice, or it may be used in supervision to generate reflection and exploration of alternative approaches. It may also be valuable for consideration when examining the structure of mental health programs, to increase efficacy of their services with this population.

### **Target Population**

The target population of this manual is all mental health professionals in a variety of professional roles. This is inclusive of counsellors, psychologists, residential treatment staff, mental health support workers, nurses, and social workers. FASD is applicable across all mental health sectors, and whether they know it or not all mental health practitioners work with individuals impacted by FASD (Rutman, 2016).

### **Benefits**

This manual may provide a valuable resource for professionals seeking to better understand the impacts of FASD and how functional limitations may impact treatment outcomes for those living with FASD. Professionals may be able to adapt service delivery based on client's functional strengths and challenges, to promote client success. As a result, individuals living with FASD may receive services that work for them, reducing the occurrence of secondary disabilities.

### **Limitations**

FASD impacts each individual uniquely and there are no set strategies that will be effective with all individuals living with the disability. As such, this manual can not be used exclusively. The challenges discussed will impact each person differently, requiring

different strategies and considerations. As such, this manual is simply a guide to help professionals identify challenges and creatively adapt to meet the clients needs.

Additionally, many of the strategies are not empirically based due to a lack of research on effective adaptations. These strategies may not be effective for all clients but can act as a starting point to generate adaptive ideas.

### **Summary**

In this chapter a brief overview of the manual was provided. Knowledge transfer, target population, benefits and limitations were also discussed. Up to 3% of Canadians are living with FASD (Centre for Addictions and Mental Health, 2018), and 90% of this population has a co-occurring mental health disorder (Pei et al., 2011). As a result, there is a high likelihood of all mental health practitioners serving individuals with FASD. To effectively support this population, it is critical for professionals to become FASD-informed, developing an understanding of the disability and how to adapt service delivery. For that purpose, this manual was developed to act as an informational resource for mental health professionals. While the information discussed is limited to what is available in the literature and to my own professional experience, it may act as a starting point from which professionals can begin to understand the challenges and accommodations relevant to this population.

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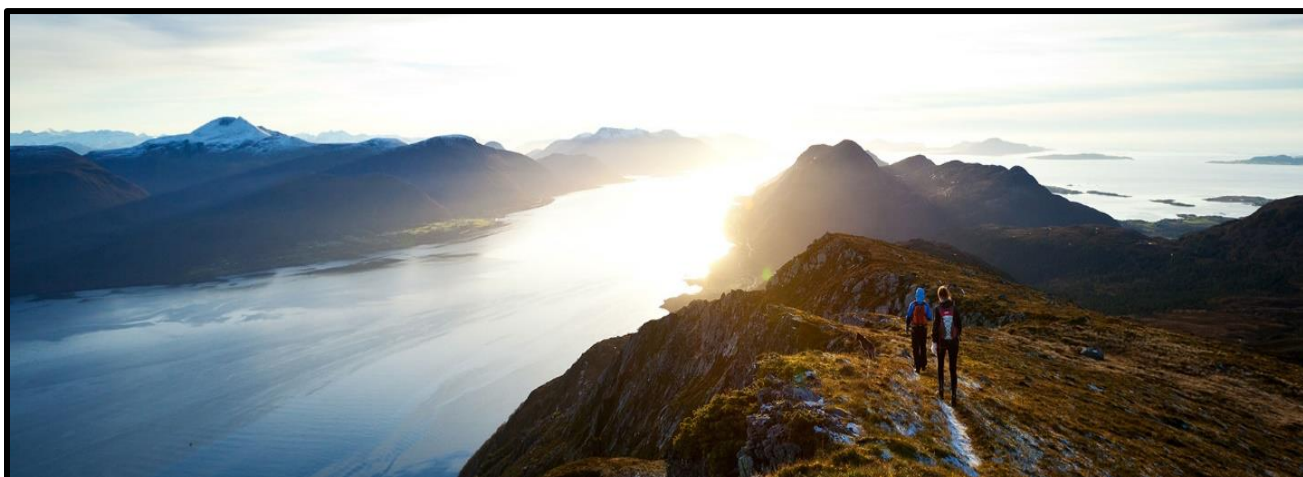
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# **FASD Informed Practice in Mental Health Care A Practitioners Manual**



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## Preamble

Fetal alcohol spectrum disorder (FASD) is the leading non-genetic cause of mental retardation in Canada (The Public Health Agency of Canada, 2004) impacting all demographic groups. Recent research by the Centre for Addiction and Mental Health (2018) suggests that the prevalence of those living with FASD in Canada is likely close to 2-3% of the population. Further, there is evidence that as much as 90% of these individuals also live with a mental health disorder (Pei, Denys, Hughes, & Rasmussen, 2011). As such, it is quite likely that all mental health practitioners will be supporting individuals impacted by FASD (Rutman, 2016).

Despite the high likelihood of those with FASD seeking mental health treatment, research demonstrates that these individuals often do not experience success in typical programs (Rutman, 2016). This is attributed in part to many programs being structured around assumptions of cognitive capacity, as well as many individuals with FASD going unidentified as they are undiagnosed or choose not to disclose a diagnosis (Rutman, 2016). These challenges present two distinct implications for mental health treatment:

***1. Mental health services professionals must be able to identify potential limitations and adapt accordingly***

***2. Mental health programs must become FASD informed, increasing accessibility for those living with FASD***

In light of these needs, this manual is intended to act as a quick reference for mental health practitioners, aiding them in adopting an FASD informed lens in their practice. Through an understanding of the impacts of FASD, and adopting an

individualized approach to practice, practitioners can increase accessibility of mental health services to this population.

**Terminology:** FASD is an umbrella term that encompasses a broad range of physical, mental, behavioral, and cognitive effects resulting from prenatal alcohol exposure. Many of those impacted by FASD go undiagnosed, and as such this manual intends to broadly capture the challenges and adaptations required by all who are impacted, regardless of their diagnostic status.

**Limitations:** Prenatal exposure to alcohol affects each individual uniquely. This manual is meant to broadly capture the range of impacts and may not reflect the functioning of each person living with FASD.

## Part One: An Introduction to FASD

FASD is caused through maternal alcohol consumption during pregnancy and results in a broad range of functional challenges (Popova, Lange, Burd, & Rehm, 2015). The effects of FASD vary significantly, resulting in most individuals with FASD having unique strengths and challenges (Rutman, 2016). Factors which influence how a fetus is impacted by alcohol exposure include the stage of prenatal development during exposure, frequency and quantity of exposure, overall health of the mother, and environmental factors (Rutman, 2016). The range of deficits frequently include cognitive, regulatory, and adaptive functioning challenges (Popova et al., 2015). While many strategies and supports can be put in place, FASD is an irreversible neurodevelopmental disability and the impacts are lifelong (Rutman, 2016).

There are many misconceptions about fetal alcohol related disorders. This may be due in part to the broad spectrum of the disorders, the stigma often associated with the disorders, and the various assessment and diagnostic approaches. To reduce misunderstandings, this section will review common myths and facts associated with FASD and breakdown the diagnosis and assessment processes. Further, risk and protective factors for those living with FASD are discussed, followed by a review of primary and secondary disabilities.

## Myths and Facts<sup>1</sup>

### ***Myth 1: You can tell someone has FASD because of their facial features***

FACT: Most people living with FASD do not have the sentinel facial features associated with the disorder. These occur only when alcohol is consumed during a very brief period of pregnancy. When the features are present they are often quite subtle.

### ***Myth 2: FASD only happens to women who struggle with addiction***

FACT: FASD occurs in many children of mothers who *do not* struggle with addiction. There is no known safe amount of alcohol that can be consumed during pregnancy and any amount puts a fetus at risk.

### ***Myth 3: FASD only happens in specific socio-economic groups***

FACT: FASD is a global health issue impacting all social groups. Contrary to popular belief, FASD is not a poverty or addiction issue. Research shows the highest rates of alcohol use during pregnancy occurs in college educated women ages 35-44.

### ***Myth 4: Alcohol consumed by the father during conception can impact the baby***

FACT: There is no direct connection between the father's alcohol consumption during conception or pregnancy and FASD. However, fathers play an important role in supporting an alcohol-free pregnancy.

### ***Myth 5: FASD is a childhood disorder***

FACT: FASD is a permanent, life-long disability affecting individuals across the life span. There are many adults currently living with FASD.

### ***Myth 6: Moderate alcohol consumption early in pregnancy is safe***

FACT: Research has not shown any safe amount of alcohol to consume during pregnancy and there is no known safe period to consume alcohol during pregnancy. No alcohol while trying to conceive or through the course of pregnancy is recommended.

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<sup>1</sup> The following information was collected from:

Calgary Fetal Alcohol Network (2017). *Fast facts*. Retrieved from <http://www.mycfan.ca/fast-facts/>

Centers for Disease Control and Prevention (2015). *One in 10 pregnant women in the United States reports drinking alcohol*. Retrieved from <https://www.cdc.gov/media/releases/2015/p0924-pregnant-alcohol.html>

## Diagnosis and Assessment

The assessment and diagnostic process of FASD is complex and multifaceted. This is due to the broad range of functional profiles of those living with FASD and the need for a multidisciplinary team to assess various domains of functioning (Astley, 2004). Adding to this is the challenge of obtaining accurate prenatal alcohol history (Benz, Rasmussen, & Andrew, 2009). To address these challenges, diagnostic models have been developed to assist clinical teams in the assessment and diagnostic process. As each model has unique diagnostic terms, and the recommended terms and criteria have changed over time, many individuals currently living with FASD have a variety of diagnoses under the FASD umbrella depending on when and where they received a diagnosis. A breakdown of the diagnostic terms and criteria is provided in Table 2. Presently, the 2015 Canadian Guidelines are recommended for diagnosis of FASD in Canada (Cook et al., 2016).

Often a diagnosis is accompanied by a functional assessment report which includes the individual's history, medical findings, diagnosis, and the results of a neurodevelopmental assessment (Cook et al., 2015a). This report will provide insight about the clients functioning related to issues such as cognition, academic achievement, memory, attention, executive and adaptive functioning, and affect (Cook et al., 2015a). As mental health professionals, the report can be used to help understand how a client learns and interacts with the world. Recommendations are typically provided and can be used to promote client success.

**Cautions about IQ:** Although an IQ score is often provided in an assessment and is used as the bench mark for most disability services, research has found that IQ does not consistently relate to executive functioning deficits (Rasmussen, 2005) or adaptive functioning deficits (Fagerlund et al., 2012). As such, clients with high IQ scores may still require flexibility and adaptations to treatment.

**Undiagnosed FASD:** Unfortunately, many individuals impacted by FASD are undiagnosed or may choose not to disclose a diagnosis (Rutman, 2016). This requires professionals to be curious and mindful of potential limitations in all clients. When



clients appear to be struggling with aspects of mental health treatment, clinicians can consider the possibility of a capacity issues, shifting focus from seeing negative behaviors to seeing functional challenges.

Table 1: Diagnostic Tools, Terms, and Criteria

Diagnostic Tool	Diagnosis	Diagnosis Description
<i>The US Institute of Medicine (IOM)</i>	<b>FAS (Fetal Alcohol Syndrome) – confirmed alcohol exposure</b>	<ul style="list-style-type: none"> <li>• Evidence of facial features associated with FAS</li> <li>• Evidence of growth impairment</li> <li>• Evidence of central nervous system neurodevelopmental abnormalities seen through physical indicators or neurological impairment</li> <li>• Evidence of prenatal alcohol exposure</li> </ul>
<i>Diagnostic criteria for the IOM was collected from Chudley et al. (2005)</i>	<b>FAS – without confirmed alcohol exposure</b>	Criteria are the same as above with the exception of confirmed alcohol exposure
	<b>Partial FAS with confirmed alcohol exposure</b>	<ul style="list-style-type: none"> <li>• Confirmed alcohol exposure</li> <li>• Evidence of some facial features associated with FAS</li> <li>• Evidence of either               <ul style="list-style-type: none"> <li>➤ Growth impairment</li> <li>➤ CNS neurodevelopmental abnormalities</li> </ul> <p style="text-align: center;"><b>or</b></p> <li>➤ Evidence of abnormal behavioral or cognitive patterns that are inconsistent with development and are not explained by other factors</li> </li></ul>
	<b>Alcohol Related Birth Defects (ARBD)</b>	<ul style="list-style-type: none"> <li>• Confirmed history of alcohol exposure</li> <li>• Presence of effects which research has identified as an observed outcome of alcohol exposure</li> </ul>
	<b>Alcohol Related Neurodevelopmental Disorder (ARND)</b>	<p>This diagnosis is given when either or both of the following are present:</p> <ul style="list-style-type: none"> <li>➤ Evidence of CNS neurodevelopmental abnormalities</li> <li>➤ Evidence of abnormal behavioral or cognitive patterns that are inconsistent</li> </ul>

		with development and are not explained by other factors
<p><i>The 4-Digit Diagnostic Code</i></p> <p><i>Diagnostic criteria for the 4-Digit Code was collected from Astley (2004)</i></p>	<b>Fetal alcohol syndrome (alcohol exposed)</b>	<ul style="list-style-type: none"> <li>• Mild to severe growth impairment is present</li> <li>• All three facial features are present and ranked severe</li> <li>• Mild to Significant CNS Damage</li> <li>• Prenatal alcohol exposure is confirmed</li> </ul>
	<b>Fetal alcohol syndrome (alcohol exposure unknown)</b>	<ul style="list-style-type: none"> <li>• Mild to severe growth impairment is present</li> <li>• All three facial features are present and ranked severe</li> <li>• Mild to Significant CNS Damage</li> <li>• Prenatal alcohol exposure is unknown</li> </ul>
	<b>Partial fetal alcohol syndrome (alcohol exposed)</b>	<ul style="list-style-type: none"> <li>• Growth impairments present, moderate facial features, mild to severe CNS damage, and confirmed alcohol exposure</li> <li><i>or</i></li> <li>• No growth impairment, moderate to severe facial features present, mild to severe CNS damage, and confirmed alcohol exposure.</li> </ul>
	<b>Static encephalopathy (alcohol exposed)</b>	<ul style="list-style-type: none"> <li>• Mild growth impairments present or none at all</li> <li>• Mild presence of facial features or none at all</li> <li>• Mild to significant presence of CNS damage</li> <li>• Confirmed prenatal alcohol exposure</li> </ul>
	<b>Static encephalopathy (exposure unknown)</b>	<ul style="list-style-type: none"> <li>• Mild growth impairments present or none at all</li> <li>• Mild presence of facial features or none at all</li> <li>• Mild to significant presence of CNS damage</li> </ul>
	<b>Neurobehavioral disorder</b>	<ul style="list-style-type: none"> <li>• Mild growth impairments present or none at all</li> <li>• Mild presence of facial features or none at all</li> <li>• CNS function is considered within the normal range</li> </ul> <p><i>This diagnosis may be given when a child is too young to formally assess and the child should be reassessed when they are older. This diagnosis may also be given when there was not enough evidence for CNS damage, but clinical judgement indicates CNS damage can not be ruled out.</i></p>

	<p>Additional Diagnostic categories which may be attached to a diagnosis listed above include:</p> <ul style="list-style-type: none"> <li>• <b>Alcohol exposed</b> (prenatal exposure has been confirmed)</li> <li>• <b>Alcohol exposure unknown</b> (alcohol exposure is not confirmed)</li> <li>• <b>Sentinel physical findings</b> (moderate to severe growth impairments or moderate to severe facial features are present)</li> </ul>	
<p><i>2015 Canadian Guidelines for Diagnosis</i></p>	<p><b>FASD with Sentinel Facial Features</b></p>	<ul style="list-style-type: none"> <li>• All three sentinel facial features are present</li> <li>• Alcohol exposure is either confirmed or unknown</li> <li>• Evidence of impairment in at least 3 neurodevelopmental domains</li> </ul>
<p><i>Diagnostic Criteria was collected from Cook et al. (2015b)</i></p>	<p><b>FASD without Sentinel Facial Features</b></p>	<ul style="list-style-type: none"> <li>• Evidence of impairment in at least 3 neurodevelopmental domains</li> <li>• Confirmation of prenatal alcohol exposure</li> </ul>
<p><i>Under these guidelines an additional designation has been added: <b>At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure</b>. This is not a diagnosis, but a designation given to indicate confirmed alcohol exposure potential for neurodevelopmental dysfunction. This designation may be given to young children who may need to be re-assessed when older to evaluate neurodevelopmental functioning.</i></p>		

## Risk and Protective Factors

In the mental health field, it is well established that life experiences and outcomes are greatly influenced by what are known as risk and protective factors. These factors can be biological, personal, or environmental in nature and they influence an individual's outcomes and stress response. Many individuals living with FASD experience much higher risk factors and adverse outcomes than the general population. Adolescents and adults living with FASD are more likely to experience housing instability and homelessness, criminality, disrupted school experiences, alcohol and drug problems, and confinement in a correctional, psychiatric, or addiction-based setting (Flannigan et al., 2017; Streissguth et al., 2004). As such, it is critical to consider risk and protective factors specific to this population in order to increase resilience and mitigate adverse outcomes. The following are risk and protective factors for individuals living with FASD have been identified in the research<sup>2</sup>:

### Risk Factors

<b>Other prenatal exposures</b>	<b>Childhood abuse/neglect</b>	<b>Periods in foster care</b>
<b>Parental substance abuse</b>	<b>Caregiver depression</b>	<b>Transient living situations</b>
<b>Parental death</b>	<b>Placement in foster care</b>	<b>Disrupted school experiences</b>

### Protective Factors

<b>Stable and nurturing home</b>	<b>Educational support</b>	<b>Early Diagnosis</b>
<b>Structure and supervision</b>	<b>Educational success</b>	<b>Having family advocates</b>
<b>Collaboration support teams</b>	<b>Supported Families</b>	<b>A positive social network</b>
<b>Access to clinical support</b>	<b>Access to financial support</b>	<b>Occupational support</b>

<sup>2</sup> The following information is compiled from the following resources:

Carmichael Olson, H., & Montague R.A. (2011). An innovative look at early intervention for children affected by prenatal alcohol exposure. In S. A. Aduabato & D. E. Cohen (Eds.), *Prenatal alcohol use and FASD: Diagnosis, assessment and new directions in research and multimodal treatment* (pp. 64-107). Retrieved from <https://depts.washington.edu/fasdpn/pdfs/chapter%20Early%20Interventions%20for%20Children.pdf>

Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., & Young, J.K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Development and Behavioral Pediatrics*, 25(4), 228-238. doi: 0196-206X/00/2504-0228. Retrieved from <https://pdfs.semanticscholar.org/17ff/c6b618bd4a73ae499c9cedc5c686e6c6dc32.pdf>

Radford-Paz, E. (2013). *Risk and protective factors for criminality among adults with FASD* (Master's thesis). Retrieved from [https://zone.biblio.laurentian.ca/bitstream/10219/2128/1/Radford-Paz\\_Elisa\\_Master\\_Thesis.pdf](https://zone.biblio.laurentian.ca/bitstream/10219/2128/1/Radford-Paz_Elisa_Master_Thesis.pdf)

## Primary and Secondary Disabilities

After exploring risk factors and adverse life experiences common to those living with FASD, it is important to distinguish the difference between **primary** and **secondary disabilities**.

**Primary disabilities** are the challenges directly resulting from prenatal alcohol exposure. These would include the central nervous system dysfunction, physical anomalies, or regulatory issues. (Streissguth et al., 2004). Primary disabilities impact functioning and capacity.

**Secondary disabilities** refer more to adverse outcomes that frequently occur after the person is born. Not only do these secondary challenges impact the well-being of the individual with FASD, but they can also bring lifelong consequences to the individual's family and support system (Carmichael Olson & Montague, 2011).

Table 2: Examples of Primary vs. Secondary Disabilities

Primary Disabilities	Secondary Disabilities
Directly Resulting from CNS dysfunction caused by prenatal alcohol exposure.	Challenges that develop during one's life and can be prevented - often influenced by the struggles related to primary disabilities.
Poor Memory	Negative Peer Relationships
Impulsivity	Depression
Problem Solving Challenges	Social Isolation
Learning Deficits	Homelessness
Emotional Dysregulation	Criminality
Slow Thought Processes	School Failure
Difficulty Expressing One's Self	Defense Mechanisms such as resistance, anger, or avoidance of important tasks

Note. Adapted from "Primary and Secondary Disabilities of FASD," by The FASD Justice Committee, 2018.

## Part Two: FASD and Mental Health

Although FASD is considered a medical condition, 90% of individuals with FASD have been described as also having mental health problems (Pei et al., 2011). Many experts consider mental health problems as secondary to FASD, likely occurring as a result of the many challenges and daily stressors individuals living with the disabilities experience. However, recent evidence suggests that mental health problems may also occur as a primary impact. Studies found that prenatal alcohol exposure can cause changes to stress pathways and stress related brain functioning, which may influence the development of stress related disorders (Green & Salmon, 2016). A number of scholars suggest that the onset of mental health disorders in this population is likely the result of both biological and environmental factors (Pei et al., 2011).

Some of the most prevalent issues are depression, mood and anxiety disorders, conduct disorder, personality disorders, and ADHD which has been seen in up to 95% of those with FASD in one study (Pei et al., 2011). It appears that disorders often start in childhood and remain consistent, or more severe, into adulthood (Pei et al 2011). With ADHD being the most commonly noted co-occurring disorder, it is important to note that ADHD can present differently in an individual with FASD (Ontario Center for Excellence for Child and Youth Mental Health, 2014). Children with FASD can have earlier onset of ADHD symptoms, show different challenges with attention, and can react differently to medications (Ontario Center for Excellence for Child and Youth Mental Health, 2014).

*FASD Informed Tip: Because there are so many factors which may influence the onset and presentation of mental health disorders, practitioners must look at the full picture, considering genetic, environmental, and disability related factors which influence a client's mental health. These factors must also be considered when developing individualized treatment plans.*

## **Problematic Substance Use**

In addition to frequent struggles with mental illness, studies have found that those impacted by FASD are also more likely than the general population to struggle with substance abuse. Multiple studies have found a strong correlation between prenatal exposure to alcohol and problematic alcohol use later in life (Pei et al., 2011). In a large study by Alati and colleagues (as cited by Pei et al., 2011), 25% of young adult participants with a PAE diagnosis also had an alcohol disorder and 6.1% were alcohol dependant. Another study of young adults out of the University of Washington found 60% of participants with an FASD diagnosis met criteria for a substance abuse disorder (Famy, Streissguth, & Unis, 1998). A third study found that prenatal alcohol exposure significantly influenced later dependence on alcohol, nicotine, and illicit drugs (Pei et al., 2011).

## **Suicidality**

Suicidality has also been identified with high frequency. Most notably, a study by Streissguth and colleagues (1996 as cited by Huggins, Grant, O'Malley, & Streissguth, 2008) found that those with FASD attempted suicide at five times the national average. Another study found that those with FASD who had attempted suicide, had higher rates of mental health diagnosis, substance use disorders, history of trauma and child abuse, and a lack of social supports (Huggins et al., 2008). It is possible that the high incidence of adverse life experiences in this population contributes to high rates of suicidality. Bell (2018) also suggests that trouble with affect regulation likely contributes to high rates of suicide in the FASD population, whose current life expectancy averages only 34 years.

## **Treatment**

Despite high instances of mental health related challenges, many individuals with FASD are excluded from, or do not experience success in mental health treatment programs. Challenges with behavior, learning, and cognitive disabilities, make it difficult for those with FASD to qualify for treatment programs and to experience success when admitted (Nicholson, 2008). Additionally, few treatment programs exist in Canada for

adults with co-occurring FASD and mental health or substance use problems (Nicholson, 2008).

There is a significant economic and societal cost associated with low success rates and frequent readmission. FASD imparts a large burden on society through the health care system, mental health and substance abuse treatment services, as well as systems such as foster care and criminal justice (Popova et al., 2015). Health care costs for a child with FASD are estimated at nine times the national average in the U.S. (U.S. Department of Health and Human Services, 2014). In Canada, the estimated health care cost associated with FASD in 2009 was over 6.7 million, with the cost for psychiatric care alone at 1.2 million, and substance use treatment between 2 and 5 million (Popova et al., 2015). These estimates are based on conservative calculations and it is suspected that the actual health care cost for individuals with FASD may be as high as 48 million annually (Popova et al., 2015). Further to the economic costs are the burdens faced by individuals not experiencing treatment success, or the grief and loss experienced by their loved ones.

### **Implications for Practice: An FASD-Informed Approach**

Individuals living with FASD present many unique challenges to mental health programs due to the diverse range of support needs and the hidden nature of the disability. There is also no single set of recommendations or accommodations that can be implemented to accommodate all individuals with FASD. Yet, it is an ethical imperative for all mental health professionals to provide accessible services and accommodations so that all people have equal access to care. To do so, an FASD informed approach to practice can be adopted. Deborah Rutman (2016) describes FASD-informed practice as starting with an understanding of the disability and how it may affect a person in various facets of life. As such, if mental health professionals hope to become FASD informed, and provide inclusive services, the first step is to understand the impacts of FASD, how deficits may present in treatment, and how to adapt treatment to promote successful outcomes. This requires addressing three important concepts in mental health practice: **Competency, Individualization, and Reflectivity.**



### ***Competency***<sup>3</sup>

Developing an understanding of FASD, engaging in related professional development opportunities, and working from an FASD-informed organizational structure is recommended by numerous experts in the field. For mental health care providers this entails having a strong understanding of FASD, access to ongoing professional development, and having access to FASD experts for consultation.

### ***Individualization***

An FASD-informed approach recognizes that prenatal exposure to alcohol impacts each individual uniquely, resulting in each client having unique strengths and challenges. As such, no blanket approach or single profile can be used to understand the needs of a client living with FASD. Instead, practitioners must remain open minded, curious, and flexible to meet the functional needs of each client, truly meeting the client where they are at.

### ***Reflectivity***

Critical self reflection, which acknowledges that the onus for adaptation is on the service providers rather than the individual with a brain-based disability, is essential to practice. This requires practitioners to reflect on how clients are responding to treatment, what challenges could be interfering with treatment, and assessing how they can adapt their approach, their language, or the environment to better meet the clients needs. Critical reflection means reframing problematic client behavior as a need and asking, “how can I adapt?”

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<sup>3</sup> The following information is compiled from the following resources:

Pei, J., Trembley, M., Pawlowski, A., & Poth, C. (2015). Best practices for FASD service delivery: Guide and evaluation tool kit. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/03/Pei-2015-Best-practices-for-FASD-service-delivery.pdf>

Rutman, D. (2016). Becoming FASD informed: Strengthening practice and programs working with women with FASD. *Substance Abuse: Research and Treatment*, 2016(Suppl. 1), 13-20. 10.4137/SART.S34543

Tremblay, M., Pei, J., Plesuk, D., Muchortow, A., Mihai, P., & Jordao, R. (2017). Development of a clinical practice model for serving clients with fetal alcohol spectrum disorder. *International Journal for the Advancement of Counselling*, 39(1), 82-97. 10.1007/s10447-017-9284-0

## Part Three: Central Nervous System Dysfunction

The central nervous system (CNS) is comprised of the human brain and spinal cord, and it controls most of human functioning. CNS dysfunction is a primary characteristic of FASD and has implications for how a client will navigate the environment, expectations, and process of mental health programs. In this section of the manual, common CNS challenges are discussed along with potential strategies to adapt treatment services.

When working with clients who have a diagnosis, information about their capacity and support needs can often be found in a diagnostic assessment report. In the absence of an assessment report, practitioners are left to play detective. As such, this chapter will review CNS functions commonly impacted by prenatal alcohol exposure, with the hopes of creating familiarity with these issues so that practitioners may be better prepared to identify client challenges and adapt accordingly. When considering CNS dysfunction, it is important to understand the following concepts:

- ✓ **Individualized Profiles:** The impact that alcohol has on the CNS depends on a number of variables, resulting in a broad range of functional profiles. Each individual will present with unique functional strengths and challenges. For some individual's impairment is somewhat consistent across domains. Others may experience major challenges in one area, but relative strength and capacity in another.
- ✓ **Interaction of domains:** The different parts of the CNS work together and rely on each other to function effectively. This means that challenges in one area will impact functioning across multiple brain domains. For example, deficits in attention, can impact other areas of functioning such as memory, comprehension, and regulation.

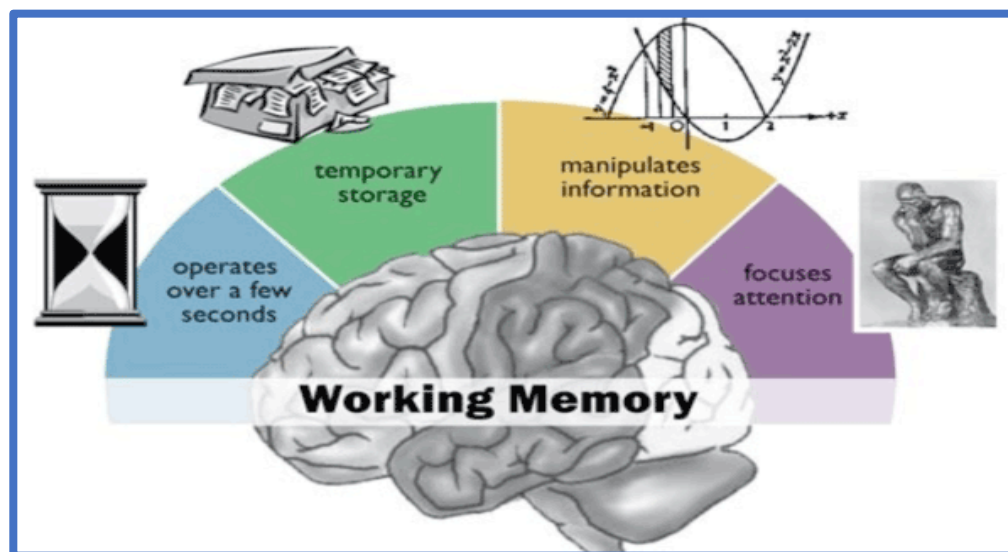
# MEMORY

The ways in which our brain uses memory are incredibly complex, involving numerous systems and functions. Memory itself involves the coding, storage, and retrieval of information but these processes are interconnected with other functional systems such as information processing, sensory input, muscle and motor memory, and attention. Further, the significance of the memory itself will influence how it is stored and retrieved. Events or information that has a significant impact on the person will be more easily retrieved from storage.

Many individuals with FASD struggle with a range of memory challenges, and at times memory difficulties can be inconsistent, meaning that the level of memory functioning can vary from one day to the next (Millar et al., 2017). Two distinct types of memory which can each be impacted by prenatal alcohol exposure include<sup>4</sup>:

**Working Memory:** Short term storage of information, previously conceptualized as short-term memory. This is where information is cognitively processed. Working memory is limited, and typically involves storage of information for a matter of seconds.

**Long Term Memory:** Information that moves beyond Working Memory, undergoing further processing, and that is held for a long period of time.



<sup>4</sup> Ormrod, J. E. (2016). *Human learning* (7th ed.). Toronto, ON: Pearson.

Table 3: Potential Challenges and Strategies for Memory

Potential Challenges	Accommodations to Support
<p>Time Management:</p> <ul style="list-style-type: none"> <li>Remembering appointments, scheduled times, purpose, location, and how to get there</li> </ul> <p><i>In mental health services, this may look like frequent missed appointments, frequently arriving late, or showing up at unscheduled times.</i></p>	<ul style="list-style-type: none"> <li>Support with utilizing time management tools such as a calendar or agenda</li> <li>Support with programming reminders in client cell phones</li> <li>Remind clients through phone or text the day before and the day of appointments</li> <li>Support individual in understanding how to get to the appointment and when to leave home in order to get there on time</li> <li>Keep appointments at the same day and time each week</li> </ul>
<p>Managing Expectations:</p> <ul style="list-style-type: none"> <li>Remembering rules and guidelines</li> <li>Remembering consequences for actions</li> <li>Remembering what needs to be done and when</li> <li>Remembering if and when a task has been completed</li> </ul> <p><i>Challenges with remembering expectations may appear like deviance or a lack of commitment to mental health treatment.</i></p>	<ul style="list-style-type: none"> <li>Keep rules and guidelines posted in clear sight</li> <li>Provide frequent reminders, cues, and coaching</li> <li>Use time management tools to include tasks and deadlines</li> <li>Use checklists</li> <li>Do not have consequences for negative choices. Instead focus on future planning and managing choices better in the future.</li> </ul>
<p>Past Events and Narratives:</p> <ul style="list-style-type: none"> <li>Remembering recent events, or remembering events from years past</li> <li>Ability to differentiate real life from fantasy</li> </ul>	<ul style="list-style-type: none"> <li>Use pictures to help clients remember timelines and personal stories</li> <li>Life books can be made in collaboration with supports</li> <li>Understand that false information may be a desire to provide an answer when the client is unsure</li> <li>Know that issues with remembering past events may impact how a client recalls and processes difficult memories in</li> </ul>

<p><i>In treatment, this may appear like “lying” or “story telling” due to struggles to accurately recall past event.</i></p>	<p>counselling. Added struggles with processing a traumatic event could be quite triggering and requires increased caution and sensitivity.</p>
<p>Daily Living:</p> <ul style="list-style-type: none"> <li>• Managing personal care such as teeth brushing, showers, or laundry</li> <li>• Remembering items in oven or on stove</li> <li>• Remembering items needed at the grocery store</li> <li>• Paying bills or rent on time</li> <li>• Home safety such as remembering to lock doors or turn off the tap</li> </ul>	<ul style="list-style-type: none"> <li>• Reminders, checklists, calendars, and timers</li> <li>• Assess client strengths and use strategies accordingly, such as visual vs. verbal cues.</li> <li>• Include natural supports in a plan for check-in’s</li> <li>• Refer to community services as needed</li> <li>• Flexibility in residential treatment and increased support</li> </ul>

# Communication

Individuals living with FASD may struggle with a variety of communication challenges. Struggles can include written or verbal communication, the ability to express oneself, the ability to articulate a need, or the ability to comprehend what is being said by others. Such challenges may impact engagement in mental health treatment by making it difficult for clients to engage in talk therapy, follow instructions, or express themselves verbally. Clients who struggle with communication may disengage or become frustrated if others around them are unable to find an effective way to engage them. This is where practitioners may need to tap into creative means of communication to support clients in benefitting from mental health services.

*Gerteisen (2008) discusses art therapy in the context of working with clients living with FASD who have experienced trauma. She explains that art therapy can provide a means of nonverbal expression at a sensory level that can easily be understood. Drawing in particular can provide stimulus to overcome difficult feelings, address issues of trauma, and provide a means of telling one's story (Gerteisen, 2008).*

Table 4: Potential Challenges and Strategies for Communication

Potential Challenges	Accommodations to Support
Receptive Language <ul style="list-style-type: none"> <li>• Verbal comprehension</li> <li>• Ability to understand instructions</li> <li>• Ability to process group-based treatments</li> <li>• Ability to engage in and comprehend meaningful conversation with others</li> </ul>	<ul style="list-style-type: none"> <li>• Use clear and concrete language</li> <li>• Break large tasks down into a few simple tasks</li> <li>• Limit how much information is given at a time</li> <li>• Provide written or visual instructions if a client has a learning preference for these modes of communication</li> </ul>

<p><i>Some individuals with comprehension challenges may easily get frustrated when they can not understand. Others may try to hide their lack of understanding with humor or negative behaviors.</i></p>	<ul style="list-style-type: none"> <li>• Check in with clients to ensure understanding and adapt as needed</li> </ul>
<p>Expressive Language</p> <ul style="list-style-type: none"> <li>• May struggle to communicate needs, feelings, or experiences</li> <li>• May struggle to retrieve words or names from memory</li> <li>• May have limited vocabulary</li> </ul>	<ul style="list-style-type: none"> <li>• Provide plenty of time and opportunities for expression</li> <li>• Provide multiple modes of communication including written, verbal, or electronic devices</li> <li>• Integrate expressive therapies such as art or music</li> </ul>
<p>Abstract Language</p> <ul style="list-style-type: none"> <li>• Understanding metaphor, idioms, or abstract instruction such as “be polite”</li> </ul>	<ul style="list-style-type: none"> <li>• Avoid metaphors and slang</li> <li>• Be direct, clear, and specific</li> </ul>
<p>Non-Verbal Communication</p> <ul style="list-style-type: none"> <li>• Challenges with reading body language or facial cues</li> <li>• Challenges identifying signs of emotions in others</li> </ul>	<ul style="list-style-type: none"> <li>• Practice identifying facial expressions and emotional cues</li> <li>• Practicing identifying a range of emotions and reactions</li> <li>• Provide coaching as needed in group settings</li> <li>• Provide social skills training</li> </ul>

# Functional Academics

Academically, individuals with FASD often struggle with deficits in reading, spelling, or math and often require special education services (Pei, Flannigan, Walls, & Rasmussen, 2016). In adulthood, these academic deficits may contribute to high rates of unemployment (Pei et al., 2016) and difficulty with daily life skills. It's important to consider that the foundational academic skills we acquire in grade school are essential for successfully navigating adult life. Foundational math and literacy allow us to make a budget, pay the bills, get groceries, read instructions, or complete applications for housing, employment, and services. Individuals with these deficits may be experiencing a variety of challenges in life prior to accessing treatment. As mental health professionals, it is critical to ensure that clients are connected to appropriate resources so that they are stable and able to engage in treatment.

*Table 5: Potential academic challenges and accommodations*

Potential Challenges	Accommodations to Support
<p>Math related Challenges:</p> <ul style="list-style-type: none"> <li>• Money management</li> <li>• Reading and managing time</li> <li>• Employment related math tasks</li> </ul>	<ul style="list-style-type: none"> <li>• Use digital clocks when needed</li> <li>• Support clients in planning for time management</li> </ul>
<p>Reading related Challenges:</p> <ul style="list-style-type: none"> <li>• Completing requested readings for treatment programs</li> <li>• Understanding and completing intake paperwork</li> <li>• Understanding written instruction</li> </ul>	<ul style="list-style-type: none"> <li>• Provide auditory or pictorial resources when appropriate</li> <li>• Take extra care to review informed consent</li> <li>• Complete paperwork together</li> </ul>
<p>Writing related Challenges:</p> <ul style="list-style-type: none"> <li>• Writing challenges may limit client ability to take notes, journal, or complete paperwork</li> </ul>	<ul style="list-style-type: none"> <li>• Provide creative alternatives for communication and expression</li> <li>• Support with filling out forms</li> </ul>



# Attention

Attention is one of the most common neurodevelopmental challenges associated with FASD (Cook et al., 2015a; Kodituwakku, 2009; Pei et al., 2011). In some studies, ADHD has been identified in up to 95% of participants (Pei et al., 2011). However, ADHD can present differently in individuals with FASD who may experience greater challenges with holding information, shifting attention, and sustaining visual attendance (Murawski, Moore, Thomas, & Riley, 2015). Further stimulants typically used to treat ADHD can have adverse effects in those with FASD, with some individuals showing no improvement to attention and some identifying increased negative outcomes on medication (Murawski et al., 2015). Such challenges could potentially act as a barrier to clients benefitting from services. However, practitioners can easily restructure service delivery to better meet the clients learning needs.

Table 6: Attention challenges and strategies

Potential Challenges	Accommodations to Support
<p>Maintaining Attention</p> <ul style="list-style-type: none"> <li>• Ability to maintain focus for an extended period of time</li> <li>• Ability to maintain focus through distractions</li> <li>• Ability to shift attention to a new activity or topic</li> </ul> <p><i>Clients struggling with attention may appear distracted, disengaged, or forgetful.</i></p>	<ul style="list-style-type: none"> <li>• Minimize distractions for important conversations</li> <li>• Keep important lessons or discussions brief</li> <li>• Take body breaks – any large motor movement that engages muscles and joints (the proprioceptive system) will support the body in calming to attend to information again</li> <li>• Be thoughtful about the time of day. If the individual is not a morning person, it may be harder to pay attention in the mornings.</li> <li>• Provide a variety of fidget tools to support individuals in regulation and consequently sustained attention. As people’s regulatory needs are unique, it is helpful to have a variety of tools to allow clients to choose what works best for them.</li> </ul>

Figure 1: Fidget Tools

# Fidget Tools

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## Jewelry



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## Balls



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## Toys



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## Miscellaneous



# PROCESSING

Information processing is commonly impacted by exposure to prenatal alcohol. Research indicates that many individuals with FASD have a slower processing speed, especially when processing complex information (Kodituwakku, 2009). This means that some individuals will need more time to consider what is being said, follow instructions, understand a question, and thoughtfully respond.

Table 7: Potential Processing Challenges and Strategies

Potential Challenges	Accommodations to Support
<p>Processing speed is a measure of how quickly one can process information and respond. Delayed processing speed may impact one's ability to fluidly engage with others, keep up with learning, respond to questions, and follow instructions.</p> <p><i>Processing delays can present like someone not responding to questions, not wanting to engage, or not following instructions. In reality they may just need more time to respond.</i></p>	<ul style="list-style-type: none"> <li>• Provide ample time to answer questions</li> <li>• Allow for quiet moments and “pauses” to create more room for processing information</li> <li>• Provide few instructions at a time to allow for processing of each step</li> </ul>



# Executive Functioning

Executive functioning deficits are a common challenge in those living with FASD and that these deficits can be present despite potentially high IQ scores (Rasmussen, 2005). This area of intelligence involves higher order cognitive processes such as inhibition, flexible thinking, planning, judgement, organization, and understanding cause and effect (Millar et al., 2017). Individuals with executive functioning challenges may struggle to plan ahead, get organized, learn from consequences, or make good decisions (Mariasine, Pei, Poth, Henneveld, & Rasmussen, 2014; Millar et al., 2017). Such challenges can have devastating consequences, impacting adult outcomes related to employment and housing. Additionally, struggles to understand consequence, manage impulses, and plan ahead, makes individuals vulnerable to negative peer influence.

*Table 8: Executive Functioning Challenges and Strategies*

Potential Challenges	Accommodations to Support
<p><b>Inhibition Control</b> Individuals who struggle with inhibition control may present as very impulsive, making decisions without much thought for the impact or outcome. For some individuals, they may struggle to control problematic behaviors such as respecting authority, taking items that don't belong to them, refraining from substance use, or skipping treatment sessions.</p> <p>For individuals struggling with mental health, this may make it difficult to follow through with treatment plans, or medication regiments.</p>	<p>Individuals who struggle with inhibition control are often doing the best they can with what they have in the moment. One of the best strategies is to increase protective supports that provide guidance, supervision, and coaching. Additional strategies include:</p> <ul style="list-style-type: none"> <li>• Teach mindfulness techniques that help slow down inhibitions</li> <li>• Role play scenarios ahead of time</li> <li>• Identify who is often around during good choices and bad choices, and help the client plan to spend more time with “good choice” friends</li> </ul>

	<ul style="list-style-type: none"> <li>• Teach that mistakes are going to happen and plan strategies for managing them</li> </ul>
<p><b>Flexible Thinking</b></p> <p>Challenges in this area may make it difficult to consider a situation from multiple perspectives or to critically evaluate assumptions or perceptions. Deficits can result in frustration when clients are being challenged beyond what their flexibility allows them.</p> <p>Flexible thinking challenges often lead to difficulty understanding abstract concepts such as time, ownership, or value.</p>	<ul style="list-style-type: none"> <li>• Set expectations based on developmental age, rather than chronological</li> <li>• Slow things down and help clients to make connections based on their own experiences</li> <li>• When necessary, make abstract concepts like ownership more concrete, using labels or clear rules.</li> </ul>
<p><b>Planning</b></p> <p>Challenges with planning can impact short term and long-term achievement. In the short term, clients may struggle to plan out their day effectively, plan their route to get to a meeting, or plan their weekend to include healthy activities.</p> <p>For long term planning they may struggle to make realistic vocational or educational plans. They may also struggle to follow through on plans that have been made because they did not plan the steps needed in between the start and finish line.</p>	<ul style="list-style-type: none"> <li>• Use mental health treatment as an opportunity to plan healthy activities and routines</li> <li>• For visual learners, use visual tools such as flow charts to explore choices, outcomes, and steps to take.</li> <li>• Help the client to identify who and how they will access support</li> <li>• For clients who struggle to plan how to get to appointments on time, help them in the planning process. Ask questions such as “what time do you think you will leave?” “what bus are you taking?” to prompt planning.</li> </ul>
<p><b>Judgement</b></p> <p>Individuals who struggle with judgement will present as commonly making poor decisions. This is not the result of poor</p>	<ul style="list-style-type: none"> <li>• Help clients develop skills to make good decisions. Practice easy decision-making tools such as</li> </ul>

intent, but a lack of ability to consider the pros, cons, and outcome of choices. This can lead to:

- Negative behaviors
- Criminal activity
- Choosing unhealthy friends
- High risk activities

weighing choices with a flow chart.

- Role play and practice decision making together to strengthen this skillset.
- Provide concrete rules about “safe” or “unsafe” people, choices, and actions.
- Focus on strengthening natural supports who can provide support and guidance for making healthy decisions

### **Cause and Effect:**

Individuals that struggle to understand cause and effect, have a hard time predicting the outcome of a behavior or choice. For some individuals, they may make the same mistake multiple times, without predicting the same negative consequence. Inability to understand cause and effect can present as:

- Individuals who do not learn from their mistakes or from consequences
- Individuals that struggle with cycles of justice involvement due to inability to predict the same outcomes or follow through on probation orders
- Individuals who appear inconsiderate of others when they struggle to predict the outcome of their words or actions
- Individuals who engage in high risk activities as they are unable to predict the risks

- When individuals struggle to connect action to outcome, focussing on consequences is likely to be ineffective. Focus instead on fixing the problem, examining the natural consequences, and planning for the future.
- When examining choices in treatment, help clients to examine the possible outcomes and how this may impact themselves and others.
- For clients on probation orders, help make each expectation into a clear rule and provide a clear consequence for breaking the rules. This can be done through plain language or pictorial probation orders.



# Adaptive Functioning

Adaptive functioning is required to meet the demands of daily life (Mariasine et al., 2014). Adaptive functioning includes communication, daily living skills, and socialization (Fagerlund et al., 2012). Research shows that adaptive functioning is commonly impacted in individuals with FASD and that these challenges can be significant regardless of an individual's IQ score (Fagerlund et al., 2012). Research also shows that adaptive functioning deficits tend to persist or worsen with age, resulting in significant impairments and maladaptive behaviors in adolescence and adulthood (Crocker, Vaurio, Riley, & Mattson, 2009; Pei et al., 2016). These challenges can impede one's ability to maintain employment or manage independent living (Mariasine et al., 2014).

*Table 9: Adaptive Functioning Challenges and Strategies*

Potential Challenges	Accommodations to Support
<p>Struggles with daily living skills may include:</p> <ul style="list-style-type: none"> <li>• Dressing appropriately</li> <li>• Maintaining cleanliness in a home</li> <li>• Managing money</li> <li>• Managing time</li> <li>• Using a telephone</li> <li>• Maintaining healthy diet</li> </ul> <p>Fagerlund et al., 2012</p>	<p>Set expectations based on developmental age, rather than chronological.</p> <p>In mental health programs, issues with time management or using a telephone may be problematic. If needed:</p> <ul style="list-style-type: none"> <li>• Provide multiple modes of communication such as text messaging and emails</li> <li>• Keep appointments at the same day and time each week</li> <li>• Ask the client what time of day is best for them</li> <li>• Help to identify strategies for remembering appointments and noticing the time such as alarms on cell phone, or phone and text message reminders.</li> <li>• Develop good routines and knowledge around healthy eating</li> </ul>

<p>Struggles with Communication:</p> <ul style="list-style-type: none"> <li>• Understanding what is being said or expressed by others</li> <li>• Knowing how to articulate one's self, express needs, or describe experiences</li> <li>• Ability to communicate effectively through writing</li> </ul> <p>Fagerlund et al., 2012</p>	<ul style="list-style-type: none"> <li>• Identify the individual's communication preferences – verbal, visual, written, and adapt accordingly</li> <li>• Give lots of time to reflect and answer questions</li> <li>• Develop capacity for identifying feelings and appropriate feeling expression – practice these throughout treatment. Tools such as feeling charts or social stories could be beneficial.</li> </ul>
<p>Struggles with Socialization:</p> <ul style="list-style-type: none"> <li>• Ability to interact with others in socially appropriate ways (Fagerlund et al., 2012).</li> <li>• May struggle with poor social boundaries, increasing vulnerability</li> <li>• May struggle with knowing how to make friends or initiate conversation</li> </ul> <p><i>Socialization challenges will likely influence one's ability to engage in group work, or to utilize natural support systems</i></p>	<ul style="list-style-type: none"> <li>• Provide extra support in group settings</li> <li>• Create flexible group programming so that clients can "pass" or adapt their level of involvement as needed</li> <li>• Provide extra coaching and guidance to the group as a whole to support the client without singling them out</li> <li>• Help the client to identify healthy vs unhealthy relationships</li> <li>• Help clients to understand appropriate boundaries with family, friends, acquaintances, and strangers</li> <li>• Utilize social stories specific to the client's situation</li> <li>• Help clients to identify support systems and plans for how and when to utilize these supports</li> </ul>



## Part Four: CNS Dysfunction and Regulation

Regulation of our physiological and neurological systems is essential to survival. We naturally regulate temperature, pain, and hunger which allows us to protect our bodies and maintain health. The regulation of sleep allows our body and mind to rest, to cope, and to function. And the regulation of affect allows us to experience psychological wellness and to engage with those around us in an emotionally functional way. Regulatory functioning relies on a variety of physiological and neurological systems being able to acquire, process, and respond to information in a coordinated effort. Individuals who are exposed to pre-natal alcohol can experience damage to the central nervous system which results in a variety of challenges with regulation. While damage to these systems often results in unique challenges to each individual, a generalization of common challenges is provided below.

### Temperature

Challenges with regulating temperature can result in individuals who are over or under responsive to temperature, leading to major weather and home safety related concerns. Individuals with this issue may not dress appropriately for extremely hot or cold weather or may not be able to monitor temperature for personal safety during daily tasks such as bathing and cooking. If temperature regulation appears to be a challenge, this can be communicated with support systems or a family physician. Community support services can help the individual create personal systems at home which help them to concretely identify what to wear or how to set temperatures. For example, individuals can be taught to use a weather app on their phone and use a chart or colored hangers to match the appropriate clothing for the day.

### Hunger

Research has found common challenges among those impacted by FASD to be poor eating habits, constant snacking, poor satiety, low appetite, and below recommended nutrient intake (Amos-Kroohs et al., 2016). Other research has found

high rates of obesity or reduced stature, and researchers have noted a high risk of nutritional deficiencies and disordered eating (Werts, Van Calcar, Wargowski, & Smith, 2014). These studies indicate possible challenges with regulating food consumption which should be considered when supporting individuals with FASD. Food intake is critical to daily functioning and may require monitoring or support to regulate healthy consumption.

## **Pain**

Regulatory challenges related to how one's brain interprets pain can cause an individual to be over or under responsive to painful stimuli. Some individuals may have too high of a pain threshold, which can result in reckless or dangerous activities. While others may have too sensitive of a threshold, resulting in what appears to be frequent complaints and avoidant behaviors. It is important to be mindful of these potential issues, as they may influence how practitioners facilitate safety and social support systems. Practitioners play a valuable role in educating supports in a client's life and understanding how the individual responds to pain a critical safety consideration to address may be. Additionally, unusual pain responses such as frequent complaints or reckless behavior could be misinterpreted as an emotional or mental health related behavior.

## **Sleep**







Sleep problems are common in this population, with studies indicating up to 85% of those living with FASD experience sleep dysfunction (Chen, Carmichael Olson, Picciano, Starr, & Owens, 2012). It has also been noted that disrupted sleep cycles are associated with health and behavioral problems such as school performance, neurocognitive deficits, inattention, unstable moods, as well as changes to metabolic and cardiovascular systems (Chen et al., 2012). As such, a lack of sleep or sleep related issues have a high impact on mental health. If sleep is a concern, MH practitioners may need to tend to this to support optimal day time functioning and treatment of MH issues.

Practitioners can support client's in developing good sleep hygiene practices and night time routines. An example of a visual sleep hygiene resource is provided in Figure 2. In addition to sleep hygiene, sensory sensitivities can impact sleep quality and should be explored. For example, tactile sensitivities may result in discomfort related to sheet or pajama fabrics. Light sensitivity may result in inability to sleep with a light coming from under a bedroom door, sound sensitivity may result in fixation on the sound of wind or a furnace running. Once sensory issues are identified they can be easily mitigated through environmental accommodations.

While working on sleep related challenges with clients, it may be beneficial to conduct sleep tracking or assessment to monitor the impact of sleep and its progression or regression. The Pittsburgh Sleep Quality Index (PSQI) has been found to be a reliable measurement of sleep quality (Buysse, Reynolds, Monk, Berman, & Kupfer, 1988; Carenter & Andrykowski, 1998). The tool has been reported as useful in psychiatric settings due to sleep's relevance in psychological well being (Buysse et al., 1988). MH practitioners interested in using this tool must be clear that the tool is for screening only, and that signs of major sleep dysfunction should result in a referral to a physician or sleep specialist (Buysse et al., 1988).

Figure 2: Sleep Hygiene

# Sleep Hygiene

-  1. Minimize screen time before bed
2. Limit caffeine intake in the afternoons and especially before bed (coffee, pop, chocolate) 
3. Minimize distracting sounds and sights 
4. Avoid taking long naps during the day 
5. Keep the bedroom quiet, dark, and cool 
6. Create a routine! Go to bed at the same time every night. Include relaxing activities in your bed time routine such as a bath or shower, meditation, or reading 

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## Sensory Systems

Sensory dysfunction is a common challenge among those living with FASD (Hansen & Jirikowic, 2013; Franklin, Deitz, Jirikowic, & Astley, 2008). Dysregulation involves unreliable interpretation and organization of sensory information (Jirikowic, Kartin, & Carmichael Olson, 2008) and it can impact areas of functioning such as adaptive behavior, learning, motor, and ability to achieve success in multiple environments (Jirikowic et al., 2008; Pei et al., 2016). Individuals with sensory dysfunction may experience significant discomfort due to how their body interprets sensory input. Helping clients to identify and manage their sensory related needs will support better mental health and increased capacity to engage effectively across environments. Mental health practitioners must be aware that:

- Sensory regulation is complex and requires ongoing assessment and strategizing.
- Each individual has a unique sensory profile. Some individuals might seek stimulation in one sense while avoiding stimulation from another sense.
- Individuals with FASD may not always be able to identify what is triggering them or what their sensory needs are. Often escalations or increased behaviors can be an indicator that something is triggering the individual.
- Practitioners may need to play detective, considering all facets of the environment to identify a trigger.
- When sensory triggers are identified, accommodations to the environment are required to support optimal functioning for the client. Clients can also be taught strategies to identify and manage their sensory needs.
- An occupational therapist can be a great resource to establish a sensory diet and routines which reduce dysregulation and increase functionality.

Table 10: Sensory Systems

	<b>Sensory System</b>	<b>Seekers</b>	<b>Avoiders</b>
<b>T O U C H</b>	<p>In treatment, moderating tactile sensory needs will increase engagement, comfort, and focus.</p> <p>Providing tactile seekers with more input will help them to feel comfortable in their body and able to focus on the material at hand.</p> <p>Avoiding triggers for tactile avoiders will reduce preoccupation and frustration.</p>	<ul style="list-style-type: none"> <li>• Provide a variety of fidgets in the treatment environment</li> <li>• Velcro underneath a table or chair allow a subtler fidget when needed</li> <li>• Jewelry can also provide a subtle fidget and source of tactile input</li> <li>• Implement resources such as kinetic sand, playdough, or puzzles into sessions</li> </ul>	<ul style="list-style-type: none"> <li>• Watch for signs of agitation that may be related to tough fabrics, paper, or furniture in the environment</li> <li>• In wilderness therapy settings, be aware of possible sensitivity to dirt, water, bark, or grass</li> <li>• In art therapy settings, be aware of paint on skin as a possible trigger. Provide brushes, water, and wipes.</li> <li>• In group settings, know that activities involving physical contact may be a trigger</li> </ul>
<b>S O U N D</b>	<p>Like touch, sound can play a large roll in a client's engagement or distractibility.</p> <p>Sound seekers may get more out of treatment when this sense is engaged.</p> <p>Sound avoiders may experience significant discomfort and struggle to engage when triggered.</p>	<ul style="list-style-type: none"> <li>• Introduce clients to white noise apps as a regulating strategy</li> <li>• Keep a clock available to allow regulation from the clocks tick</li> <li>• Teach relaxation through music with a slow or moderate beat</li> </ul>	<ul style="list-style-type: none"> <li>• Be aware that individuals with sensitivity to sound can become preoccupied and uncomfortable with minor sounds such as running water or a fan</li> <li>• Try to reduce outside noise as much as possible</li> <li>• Minimize unpredictable or loud noises which may startle a sensitive client</li> </ul>
<b>T A S T E</b>	<p>While taste may not factor into many mental health programs, it can play a role in residential treatment.</p>	<ul style="list-style-type: none"> <li>• Taste seekers may gravitate towards bold flavors found in candy, chips, or pickles. Help clients to try healthy alternatives with bold flavour. Consult with an occupational therapist when needed.</li> </ul>	<ul style="list-style-type: none"> <li>• Some individuals with sensitivities to taste will present as extremely picky eaters. Often these individuals need support from an occupational therapist or dietician to find a healthy diet that meets their sensory needs.</li> </ul>
<b>S M E</b>	<p>Smell can be used to enhance engagement, relax the nervous system, or wake up the brain in preparation for learning.</p>	<ul style="list-style-type: none"> <li>• Have clients identify scent preferences</li> </ul>	<ul style="list-style-type: none"> <li>• If clients have sensitivity to smell, ensure that scent related tools are removed prior to meeting with this client</li> </ul>

L L	<p>For client's who are sensitive to smell, its important to know that even subtle scents such as a peer's shampoo or deodorant, can cause discomfort and distraction.</p>	<ul style="list-style-type: none"> <li>• Incorporate calming scents into MH treatment through candles or essential oils</li> <li>• Keeping a variety of essential oils on hand, and let clients pick one to use during a session</li> <li>• With children, incorporate fun scents such as smelly markers or stickers</li> </ul>	<ul style="list-style-type: none"> <li>• Air out the room with an open window prior to sessions</li> <li>• Avoid using scented products to clear the environment where programming takes place</li> <li>• Avoid personal hygiene items with strong scents</li> </ul>
V I S U A L	<p>Visual stimulation is an important consideration for MH practitioners, who need to be aware of lighting, electronic use, and environmental décor.</p>	<ul style="list-style-type: none"> <li>• Incorporate visual stimulation such as videos and visual tools</li> <li>• Incorporate bright colors through art techniques</li> <li>• Provide fidgets which are visually stimulating through their color, material, or movements.</li> </ul>	<ul style="list-style-type: none"> <li>• Keep soft lighting and avoid the use of fluorescents</li> <li>• Minimize busy décor in the environment</li> </ul>
V E S T I B U L A R	<p>This system is involved in one's sense of balance, body awareness, and coordination.</p> <p>Some individuals may avoid vestibular input which comes from fast movement, such as spinning, rides, or elevators.</p> <p>Some individuals may seek extra vestibular input to help them feel in control of their body.</p>	<ul style="list-style-type: none"> <li>• Avoid experiential activities which involve large head movement or heights</li> <li>• Gentle movements like yoga may be preferred</li> <li>• Ensure all stairs have secure railings for felt security</li> <li>• Be aware that refusal to engage in a movement activity may be due to a lack of felt safety in one's physical stability</li> </ul>	<ul style="list-style-type: none"> <li>• Incorporate increased movement into therapy</li> <li>• By facilitating increased movement, vestibular seekers can remain regulated and engaged in programming.</li> <li>• Provide yoga ball to sit on in sessions</li> <li>• Provide spinning chair</li> <li>• Incorporate body breaks into service delivery</li> </ul>
P R O P R I O C E	<p>This system involves input from muscles and joints that helps the body to coordinate, feel in control of its self, and feel relaxed.</p> <p>Some individuals may be sensitive to proprioceptive input, avoiding some physical activities and touch.</p>	<ul style="list-style-type: none"> <li>• These individuals may struggle with physical touch or physical activities</li> <li>• Make adaptations that involve light touch and contact with the environment to make activities more comfortable for them</li> </ul>	<ul style="list-style-type: none"> <li>• Seekers may constantly seem like their bodies are moving, because they need to! Find ways to help them get physical input before or during sessions so they are able to remain comfortable and engaged</li> <li>• Use exercise bands to allow them to activate their muscles</li> </ul>

<b>P T I V E</b>	Others may seek input to feel comfortable and in control. These individuals will seek activities and touch that stimulates their muscles and joints such as stretching, jumping, and rough housing.	<ul style="list-style-type: none"> <li>• These individuals may be fearful of activities such as climbing or steep stairs</li> <li>• Understand that a lack of engagement in related activities may be due to discomfort</li> </ul>	<ul style="list-style-type: none"> <li>• Engage in walk-therapy</li> <li>• Incorporate body breaks and large muscle activities before sit down activities (yoga, mini trampoline, stretching)</li> </ul>
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## Affect

Research indicates a high prevalence of affect related disorders in those impacted by prenatal alcohol exposure (Pei et al., 2011; Popova et al., 2016). Affect regulation is one's ability to maintain wellbeing, manage their emotional state, and respond appropriately. For individuals who struggle with affect regulation, they may struggle to understand emotions in themselves and others, to respond appropriately to a variety of events, or to express appropriate emotional reactions towards others. They may also struggle to control intense emotions, resulting in major escalations that are beyond their control. From a neurobiological perspective, there is evidence that prenatal exposure changes neuropathways related to stress and mental health (Cook et al., 2015a; Green & Salmon, 2016;) and this may contribute to challenges with coping and regulating ones stress response.

Affect regulation is needed to maintain good mental health, which results in a broad range of mental health challenges in the FASD population who commonly struggle in this domain. For client's who come to treatment with a mental health diagnoses, this can provide insight into how the individual experiences affect and emotion. However, many clients who do not have a mental health diagnosis will still demonstrate affect-related challenges that can profoundly impact them. For many individuals who struggle in this domain, emotional regulation training can be hugely beneficial. A number of clinical models for emotional regulation exist and can be applied or adapted to meet the needs of a client. Potential goals which may be identified with a client include:



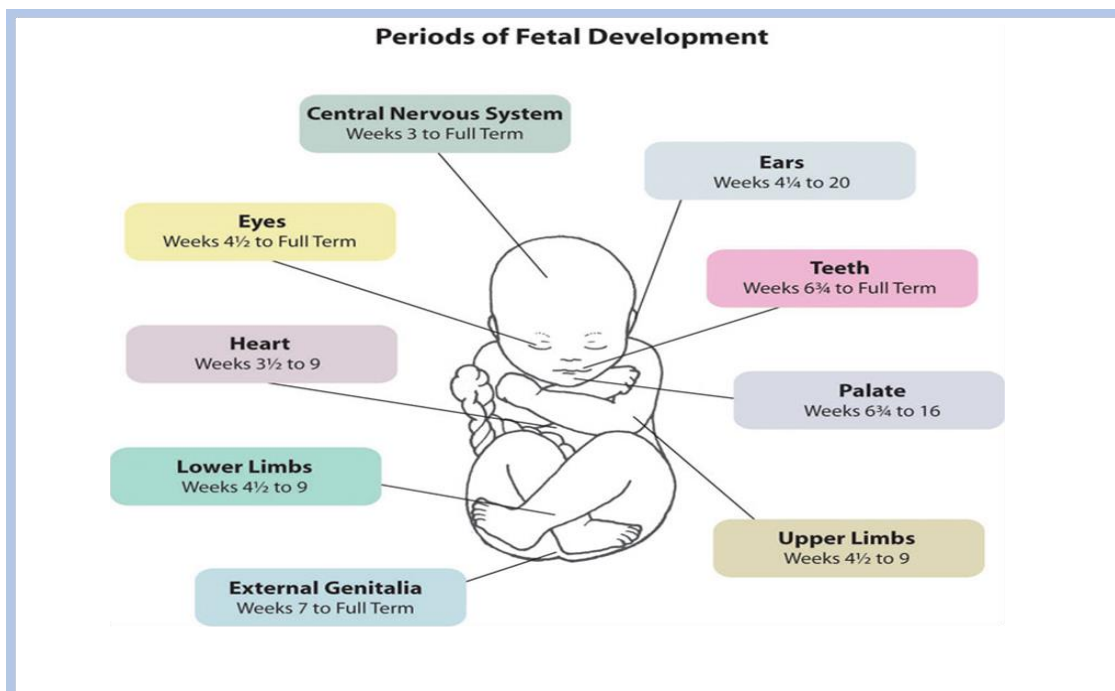
- Increase emotional vocabulary
- Identifying emotions and emotional triggers
- Identifying emotion in others, by expression and behavior, and how to respond
- Self soothing and calming strategies
- Acceptance of big emotions, and safely managing these
- Healthy coping strategies – potentially inclusive of sensory tools

***Resource: The Zones of Regulation by Leah M. Kuypers or Emotion Works by Claire Murray are great resources for teaching emotional regulation. Information on these resources is provided in the additional resources section of the manual.***

## Part Five: A Whole-Body Disorder

FASD is a whole-body disorder, with a variety of potential impacts across all of the bodies systems. While FASD is commonly associated with brain-based deficits, it is important to note that impacts have been seen among skeletal and muscular systems, as well as organ development. The broad impacts are due to alcohol acting as a teratogen which can damage the developing cells of which ever fetal systems are developing at the time of exposure (Badry, Hickey, & the Tri Province FASD Research Team, 2014). Throughout prenatal development, specific systems are especially vulnerable to alcohols effects during specific time periods. While the central nervous system is vulnerable throughout pregnancy, resulting in many neurological and regulatory impacts, other systems which have shorter windows can also be impacted (Badry et al., 2014). Alcohol exposure to many systems throughout the body can result in adults who have challenges that reach far beyond brain function. Physical challenges or ailments not only impact one’s ability to engage in treatment and achieve wellness, they also result in individuals who may require broader support and collaborative services to address a variety of needs.

Figure 3: Periods of Fetal Development



## Motor and Movement

Motor and movement, and the sense of being in control of one's body, relies on well functioning muscular and skeletal systems, as well as the central nervous system. When the development of these systems is altered due to prenatal alcohol exposure, a variety of motor and movement related challenges can occur. Challenges and accommodations can be seen in Table 11.

Table 11: Motor and Movement Challenges and Strategies

Potential Challenges	Accommodations to Support
<p><b>Fine Motor</b> Fine motor deficits may result in challenges using eating utensils, writing, or engaging in creative activities.</p>	<ul style="list-style-type: none"> <li>• Help clients to complete paperwork by writing for them</li> <li>• Adapt expressive art activities which use fine motor to support clients with engagement. For example, provide pre-cut magazine pieces for collaging.</li> <li>• Incorporate art activities that do not require precision or accuracy if needed</li> </ul>
<p><b>Graphomotor</b> This is the ability of the brain to coordinate vision and movement and deficits may also limit fine motor activities.</p>	
<p><b>Gross Motor:</b> Gross motor challenges may limit capacity for large motor movements. This is especially applicable to movement and adventure-based therapies.</p>	<ul style="list-style-type: none"> <li>• Consider resistance or frustration during physical activities as a potential sign of motor deficits</li> <li>• For clients who tire quickly, incorporate frequent short intervals of movement</li> <li>• Clients with balance issues may require supportive seating in a treatment setting</li> </ul>
<p><b>Muscle Tone:</b> Reduced muscle tone and strength may result in physical limitations and a tendency to be easily fatigued.</p>	
<p><b>Reflexes, Balance, Coordination:</b> Challenges in these areas not only impact engagement in physical activities but can also result in poor awareness and control of one's body in day-to-day life.</p>	

## Co-Morbidity of Physical Conditions

In addition to growth and motor, many other physical challenges and comorbid disorders have been reported. Research has found high rates of the following issues among this population<sup>5</sup>:

- Microcephaly
- Joint limitations
- Heart Deficits
- Spinal Malformation
- Cleft lip and cleft palate
- Urinary System Malformation
- Musculoskeletal Deformities
- Respiratory Dysfunction
- Digestive Dysfunction
- Organ related dysfunction

A study by Stade, Stevens, Ungar, Beyene, and Koren (2006) found that children and youth with FASD have significantly lower health related quality of life than those of the general Canadian population. Additionally, a recent self-report survey by Travis, Himmelreich, and Lutke, which is yet to be published, found that individuals with FASD report much higher incidences of health conditions than the general population (Givetash, 2017). Some of the conditions more frequently reported by these individuals include rheumatoid arthritis, celiac disease, and autoimmune or cardiovascular disease (Givetash, 2017). As mental health practitioners, it is important to be aware of high incidence of physical ailments, and to encourage medical support when appropriate.

Wholistic care, which includes collaboration with medical professionals, supporting client access to medical services, and consultation with occupational therapists may be especially critical for facilitating wellness in those living with FASD. Mental illness must be treated in conjunction with other areas of wellness to promote long term success.

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<sup>5</sup> The following information is compiled from the following resources:

Del Campo, M., & Jones, K. L. (2016). A review of the physical features of the fetal alcohol spectrum disorders. *European Journal of Medical Genetics*, 60(1), 55-64. 10.1016/j.ejmg.2016.10.004

Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A.E., Mukherjee, D.B., & Rehm, J. (2016). Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis. *The Lancet*, 387(10022), 978-987. doi:10.1016/S0140-6736(15)01345-8

## Part Six: Practice Considerations to Promote Success

### Intake and Assessment

The intake process provides valuable opportunity to assess client functioning and to adapt the consent process as needed. Gaining an understanding of a client's functioning during the intake process allows practitioners to better accommodate challenges and increase opportunities for success from the start. Further, assessment of functioning during initial treatment sessions is applicable across programs, regardless of whether clients with FASD have been identified. Many individuals with FASD go undiagnosed or will not report the diagnosis to professionals. Additionally, in the mental health field, many of the clients served live with functional challenges resulting from a variety of issues such as trauma, addiction, or serious mental health conditions

#### 1. Screening for Cognitive Limitations

An intake process should involve gathering information to gain a full picture of the client and their needs, and this includes functional needs. During intake, information about learning preferences and history should be collected to help build a picture of the client's functioning and how they will learn best in a therapeutic environment. Asking questions about any existing diagnosis also opens up the door to valuable insight about how someone functions. If an individual has a diagnosis related to FASD, requesting a copy of the diagnostic assessment report can provide valuable information about functioning, learning, and strategies.





#### 2. Informed Consent

Informed consent is dependant on client understanding. During the consent process, practitioners should be checking for understanding and practice flexibility to ensure the

client understands all of the risks, benefits, and limitations of services, as well as what to expect. Informed consent can be adapted through:

- Providing information through both written and verbal means
- Providing a video of informed consent
- Providing visual pictures to aid in understanding
- Use examples to explore the risks, benefits, and what to expect
- Use social stories, such as the one seen in Figure 4.

Figure 4: Informed Consent Social Story

<b><i>Talking about Bad Memories</i></b>			
<p>In counselling, sometimes we talk about bad memories.</p>	<p>This can be hard to talk about and it can bring up tough emotions.</p>	<p>It can also make us feel better and help us to heal.</p>	<p><b>YOU are in control. You choose what to talk about and when to stop.</b></p>
			

### 3. Consideration for a Legal Guardian

When working with clients with developmental disabilities such as FASD, it is critical to enquire about a legal guardian who will need to provide consent for services on behalf of the client. A legal guardian can be a relative or parent, or it can be a public guardian. Conversation with the guardian about their involvement should take place to agree to terms and information sharing boundaries that respect the client's needs as well as their autonomy and privacy.

## Promising Counselling Practices<sup>6</sup>

A number of generalized counselling strategies have been recommended by FASD experts and can be used in counselling practice with clients living with FASD. Not all strategies will work with each client, but they may provide valuable starting points as counsellors learn about each client's unique needs in the counselling relationship.

- ✓ Provide a structured and routine environment
- ✓ Keep it simple – focus on only one or two tasks at a time
- ✓ Create simple rules around counselling expectations, share them early in the counselling relationship, and share them frequently throughout service delivery
- ✓ Avoid punitive measures when clients are unable to meet expectations
- ✓ Take a holistic approach to care, focussing on all areas of living and wellness
- ✓ Be aware that many clients will experience co-occurring disorders
- ✓ Include the individual, as well as their support system in treatment planning and learning new skills
- ✓ Avoid cognitive and insight-based therapies, focussing instead on experiential approaches that involve modeling, coaching, and skill building

***Some experts recommend expressive or experiential therapies such as expressive arts, dance, music, play, or animal assisted therapy.***

<sup>6</sup> The following information is compiled from the following resources:

Akram, M., & Khan, M. I. (2017). Expressive psychotherapies for the children with intellectual disabilities. *International journal of innovative research and advanced studies*, 4(6), 348-353. Retrieved from [http://www.ijiras.com/2017/Vol\\_4-Issue\\_6/paper\\_60.pdf](http://www.ijiras.com/2017/Vol_4-Issue_6/paper_60.pdf)

Brown, J. (2017). FASD: A guide for mental health professionals. *Counselling Today*. Retrieved from <https://ct.counseling.org/2017/07/fasd-guide-mental-health-professionals/>

Bugher, E. R., & Brown, J. (2016). Art therapy and FASD: A promising treatment approach. *Forensic Scholars Today*, 2(2), 1-5. Retrieved from <https://1q5krviw73e3rlh854lufacx-wpengine.netdna-ssl.com/wp-content/uploads/2016/10/FST-2.2-Art-Therapy-and-FASD-A-Promising-Treatment-Approach.pdf>

U.S. Department of Health and Human Services. (2014). A treatment improvement protocol: Addressing fetal alcohol spectrum disorders. Retrieved from <http://depts.washington.edu/fasdpn/pdfs/TIPS2014FASDpublished.pdf>

## Strengths Assessment and Strength Based Supports

A positive strengths-based approach is recommended as best practice in service delivery for individuals living with FASD (Pei et al., 2015). For many individuals living with FASD, their deficits have been a point of focus and often they are overly aware of what they can not do. Focussing on strengths highlights their abilities, interests, and capacity. It utilizes learning preferences and personal interests to build capacity in other areas and promote a positive sense of self which is highly conducive to good mental health. In doing so, the client is able to strengthen healthy behaviors and focus more on positive areas of development, reducing other risk factors. The following are important considerations for strengths-based work with this population<sup>7</sup>:

- ✓ Help clients to recognize personal strengths even when the client cannot
- ✓ Emphasize client strengths, achievements, and examples of resiliency
- ✓ Tap into client strengths and interests when developing treatment plans and coping strategies
- ✓ Recognize that dysfunctional behaviors are the result of a disability and life challenges, rather than poor intentions
- ✓ Reframe problem behaviors as coping mechanisms and examples of resilience while shifting the client towards more effective strategies
- ✓ Encourage supports to shift from consequencing dysfunctional behavior to creating adaptations that support positive behaviors
- ✓ Use person first language, ensuring that the client is viewed and treated as a unique and valuable individual. Person first language involves shifting from “an FASD client” to “a client living with FASD”

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<sup>7</sup> The following information is compiled from the following resources:

Pei, J., Trembley, M., Pawlowski, A., & Poth, C. (2015). Best practices for FASD service delivery: Guide and evaluation tool kit. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/03/Pei-2015-Best-practices-for-FASD-service-delivery.pdf>

Rutman, D. (2016). Becoming FASD informed: Strengthening practice and programs working with women with FASD. *Substance Abuse: Research and Treatment*, 2016(Suppl. 1), 13-20. 10.4137/SART.S34543



## Promoting Self-Advocacy

As part of a holistic approach to care, mental health practitioners should focus on equipping individuals living with FASD to be self-advocates. It is important that they are able to speak up for themselves when navigating various systems, so that they receive appropriate services and care. The literature suggests that individuals with disabilities should be equipped with:<sup>8</sup>

1. Knowledge about themselves, their diagnosis, their strengths and challenges, and their learning preferences
2. Knowledge of their rights as individuals living with disabilities and as individuals navigating systems such as public health or justice
3. Communication and assertiveness skills to articulate their needs and to say no when they do not want a service or when they are uncomfortable

Strategies for mental health professionals to promote self-advocacy skills include:

- ✓ Involve individuals in goal setting and future planning to strengthen their ability to speak for themselves and identify their needs<sup>9</sup>
- ✓ Use role play or social scripting to practice self-advocacy in a variety of settings<sup>9</sup>
- ✓ Use visuals, lists, and social stories to help clients understand their rights in various settings, including with others in positions of authority such as police, medical doctors, care providers, and counsellors
- ✓ Use informed consent to ensure a client understands their rights in counselling
- ✓ Walk clients through the grievance procedure, and use this as a tool to emphasize the importance of speaking up when something is not right

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<sup>8</sup> The following information is adapted from the following resource:

Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education, 26*(1), 43-54. doi:10.1177/07419325050260010601

<sup>9</sup> The following information is adapted from the following resource:

The Alberta Learning's Special Programs Branch. (2004). *Teaching students with fetal alcohol spectrum disorder: Building strengths, creating hope*. Retrieved from <https://education.alberta.ca/media/385139/teaching-students-with-fasd-2004.pdf>

## Basic Needs, Safety Planning, and Collaboration

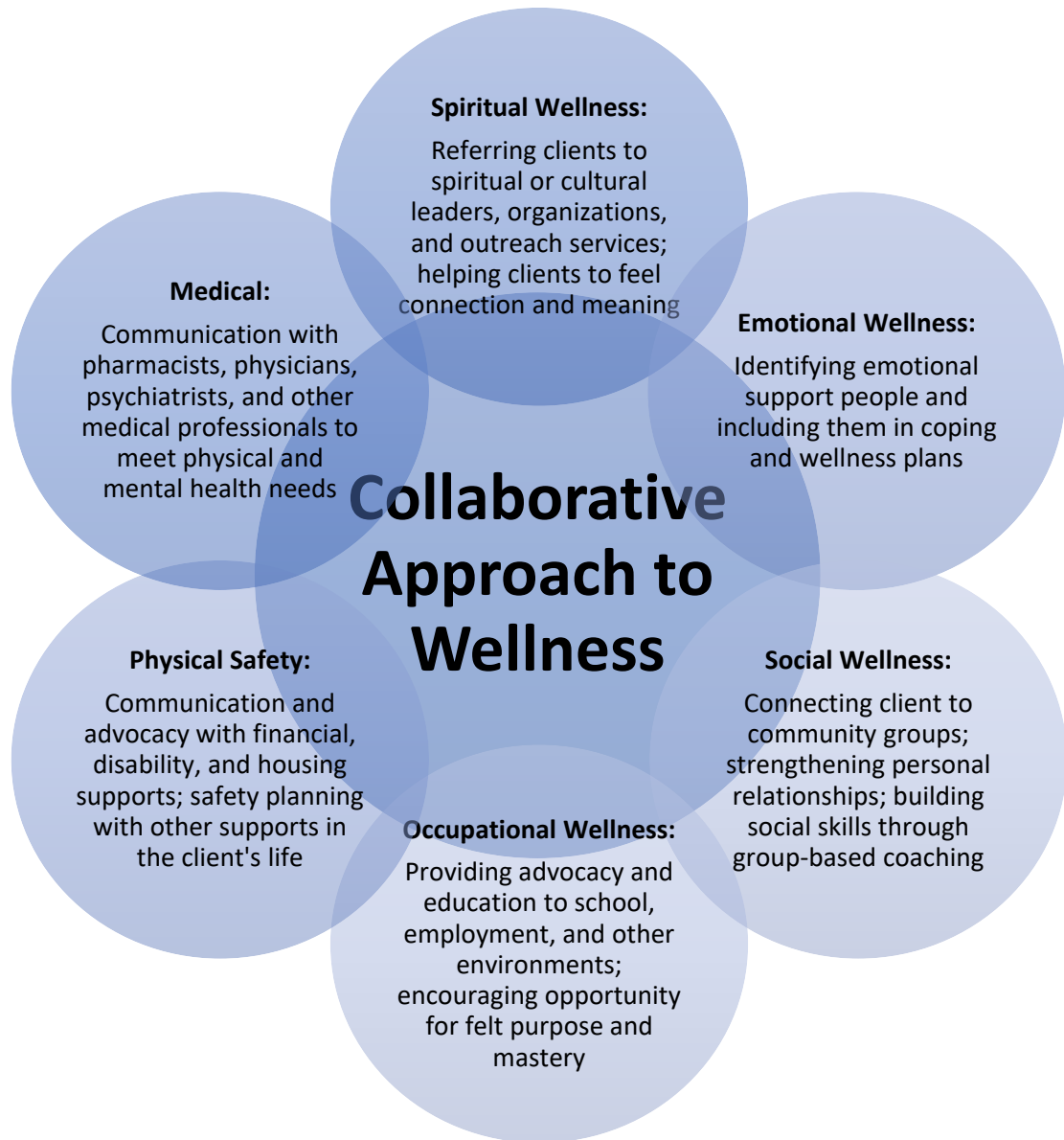
It is critical that individuals with FASD receive wholistic treatment to address a variety of issues which influence their mental health and wellbeing. If clients are struggling with issues related to housing, medication, childcare, or employment, it may be challenging for them to focus on their mental health and experience long term benefits from treatment. As these clients are more likely to experience a variety of major life challenges, treatment must focus on the big picture of well being. A collaborative approach to care is frequently suggested to address the variety of client needs which may be present (Pei et al., 2015; Rutman, 2016; Tremblay et al., 2017). Many mental health programs are not equipped to address all of the issues which clients may face, but collaborative practice allows communication with other supports who potentially can. From an organizational level, it is recommended that practitioners have built in time to allow for communication with other professionals to occur (Pei et al., 2015).

Safety planning is an important consideration to address basic needs. As many individuals with FASD struggle with impulsiveness, navigating challenging social situations, identifying safe people, among other challenges, they are frequently vulnerable to risk. Individuals with FASD are often taken advantage of or can find themselves in trouble. Safety planning is critical to try and reduce risk. Safety planning should occur with natural and professional supports in a way that makes sense to the individual.



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Figure 5: Collaborative Approach to Wellness



## Long Term Support and Re-Access

The impacts of FASD are life-long, and individuals living with FASD often require life long supports. This is inclusive to mental health supports. Mental health treatment can help individuals in dealing with past trauma, managing present challenges, develop strong coping and supports, and so on. However, due to challenges with memory, impulsivity, social skills, and affect regulation, mental health challenges are likely to be ongoing and recurrent throughout the life span. Additionally, higher likelihood of adverse experiences makes these individuals vulnerable to victimization and more likely to experience traumatic events in the future. With this in mind, mental health services must focus on a long-term approach considering future needs and the potential for re-access of services. Rutman (2016) suggests that flexibility is critical in terms of program duration. For programs with short-term models, flexibility in this structure is important. Some programs operate on a re-access basis, allowing discharged clients to return as needed in the future. Additionally, when programs are unable to provide long-term support, they can provide information and referral to alternative long-term services.

*FASD Informed Tip: Missed appointments are often the result of brain-based limitations which prevent an individual from successfully remembering and attending appointments. FASD Informed programs allow for flexibility and forgiveness of absenteeism. Programs with “3-strikes-your-out” policies limit opportunities for success and punish individuals who are experiencing additional barriers.*

## Family and Natural Supports

Natural supports include non-professionals involved in a client's life such as family members, friends, or neighbors. These supports increase an individual's quality of life and personal safety. For clients living with FASD who are struggling with mental illness, natural supports are likely the biggest influence on maintaining positive long-term change. Natural supports can remind the individual of their coping strategies and safety plans, they can advocate for appropriate supports and services, help with making accommodations to the environment that increase the client's ability to care for themselves, and help with many of the tasks required to function successfully as an adult. These supports are fundamental to the success of an individual with any developmental disability. As part of mental health treatment, practitioners must consider the role of natural supports and work to establish a healthy network of people that will support this individual going forward.

Strategies for identifying natural supports include:

- Use of a genogram that includes significant people outside of the client's family
- Ask about family, friends, and support people as part of intake
- Ask who the client looks to for support, who is often there for them, and who cares about their success

Exploring natural supports may also provide insight into social-emotional issues that influence the client's mental health. Counselling opportunities related to supports may include:

- Understanding relational issues that may be present
- Identifying potential patterns of attachment or relational trauma
- Identifying social-emotional strengths and barriers
- Explore "healthy supports" vs "unhealthy supports" to identify if some people listed are positive or negative influences.

***Rutman (2016) states that "FASD-informed programming recognizes the critical role that healthy family and support people play in the lives of adults with FASD."***

## Family Challenges

Caring for someone with a disability can be extraordinarily hard, and many supports become burnt out or distance themselves from the individual. Often, supports do not know the individual has a disability or they do not understand the disability, which can increase frustration, misunderstandings, and feelings of anger or resentment for misunderstood behavior patterns. As a result, individuals with FASD can often become isolated or experience inconsistent social support. For mental health professionals there is opportunity to mend relationships and strengthen the client's network. This may involve incorporating family therapy into programming, working with supports to better understand the individual's behaviors and challenges, and supporting the client with relational skill development to better maintain supports in the future.

For family in particular whether biological, foster, or adoptive, there are significant emotional challenges which can accompany caring for a loved one with FASD. Family members do not always know where to turn for support, and many of the people in their lives do not understand the challenges experience. Having a variety of resources which can be offered to families is important. This may include community-based caregiver support programs, peer support groups, mentorship programs, or other FASD informed counselling supports. Practitioners should be aware of common psychological challenges that occur for families of an individual living with FASD:

- ✓ **Grief and Loss:** Families often experience tremendous grief over a new diagnosis, the loss of what they anticipated for their child's future, watching the loved one struggle with addiction or mental illness, and often chronic toxic stress.
- ✓ **Fear:** For individuals who are especially vulnerable, there is a significant amount of fear experienced by loved ones. Fears may be related to issues of social vulnerability, physical safety, ability to navigate the world. For some families, there is significant fear for individuals who may be criminally or sexually taken advantage of, or who begin to associate with negative peer influences.

- ✓ **Guilt:** The guilt associated with FASD can be complex. For biological parents, there is often significant guilt associated to the alcohol exposure resulting in life long impacts. For many family members, they may feel guilty for feelings of frustration, resentment, or anger.
- ✓ **Stigma:** Due to the nature of the disability, there is significant stigma associated to the diagnosis of FASD. This can be especially difficult for biological parents but can also be challenges for other natural supports who love and care for the effected individual.
- ✓ **Family Division:** Some families struggle to be on the same page in their approach to supporting the individual, or they may experience strained relationships due to stress.
- ✓ **Attachment Challenges:** There can often be attachment challenges for both the individual living with FASD, who may have been exposed to major attachment disruption early in life, as well as the caregivers. An individual with FASD may struggle to engage in reciprocal caring, following through, empathizing, or considering the emotional needs of the support person. This can cause supports to struggle in their feelings of attachment towards the individual with the disability or to question the nature of the attachment relationship.

## Ongoing Professional Development

There is expert consensus that professionals supporting individuals with FASD should have access to ongoing professional development and consultation specific to this disability (Brown et al., 2018; Rutman, 2016; Tremblay et al., 2017). Strategies to access further information about FASD include:

- ✓ Contact local FASD networks, collaboratives, or consultants for local resources
- ✓ Attend trainings and conferences that focus on FASD
- ✓ Access webinars and online trainings
- ✓ Review resources on page 109 of this manual

Steps to maintain reflective FASD-informed practice include:

- ✓ Seek consultation opportunities with FASD experts
- ✓ Stay up to date on current research and best practices related to FASD
- ✓ Incorporate exploration of client challenges and potential strategies into professional supervision



## Concluding Remarks

Individuals living with FASD experience mental illness at disproportionate rates to the general population (Pei et al., 2011). However, due to a variety of barriers, they frequently do not experience success in mental health treatment (Rutman, 2016). Not only does this have significant consequences for the individual and their loved ones, it also places a large social and economic burden on communities and society as a whole. As with any individual living with a disability, it is an ethical imperative to adapt service delivery to accommodate their needs. The information and strategies provided in this manual are intended to support mental health professionals in creatively adapting their practice to meet the needs of each individual living with FASD. It is the author's hope that through doing so, individuals with FASD may receive mental health support that works for them, allowing them the opportunity to experience wellness and to reach their full potential.

## Additional Resources

CanFASD: Canada FASD Research Network

<https://canfasd.ca/>

FASD and Child Welfare Community of Practice Caregiver curriculum on FASD 2014

<http://www.fasdchildwelfare.ca/learning/caregivers>

Canadian Association of Paediatric Health Centres FASD Webinar Series

<https://www.caphc.org/fasd/fasd-webinar-series/>

The FASD Justice Committee

<https://fasdjustice.ca/about-mainmenu-132.html>

The University of Washington FAS Diagnostic & Prevention Network

<https://depts.washington.edu/fasdpn/>

FASD Waterloo Region

<https://www.fasdwaterlooregion.ca/learn-about-fasd>

FASD Outreach eLearning Videos

<https://www.fasdoutreach.ca/elearning/understanding-fasd>

Alberta Government FASD Resources

<http://fasd.alberta.ca/>

FASD Tool Kit for Aboriginal Families

<http://ofifc.org/sites/default/files/docs/FASD%20Toolkit%20-%202008-01.pdf>

The Zones of Regulation

<http://www.zonesofregulation.com>

Emotion Works

<https://www.emotionworks.org.uk/>

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